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OXFORD REGIONAL TRAINING COURSE IN CLINICAL PSYCHOLOGY

Submission of Dissertation

**A Study to Assess the Validity and  
Reliability of a Measure of Self-esteem,  
Stigma and Aspirations / Expectations for  
People with Learning Disabilities**

Janet M. Hitchen

Approximate Number of Words: 25 000

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OU/BPS Doctorate in Clinical Psychology

*Date of award: 10<sup>th</sup> September 1996*



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## ABSTRACT

The area of self-esteem in people with learning disabilities has been largely neglected, and previous researchers have employed a variety of approaches. It is important to further our understanding in the context of providing appropriate clinical interventions and in monitoring the effect of social policy developments on the individuals at the receiving end of service provision.

The study aimed to assess the reliability and validity of a set of measures devised specifically for use with learning disabled people, by Szivos-Bach (1993). The measures assess social comparisons, perception of stigma and aspirations and expectations. The study was carried out with 30 adults with mild and moderate learning disabilities between the ages of 18 and 65.

The results provide initial support for the social comparisons test as a measure of self-esteem. Less evidence was found for the stigma questionnaire and the aspirations-expectations test. The results are discussed in the light of comparable research into self-esteem measures with non-learning disabled populations. Further research is required, and the most profitable way forward seems to be development of multi-dimensional measures of self-esteem.

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## **Section 1: INTRODUCTION**

The need to be viewed positively is thought to be universal (Harre & Lamb, 1983). Positive self-esteem is related to "a secure, accepting environment", irrespective of age or socio-economic status (Harre & Lamb, 1983) and is associated with "stable and growth-producing relationships" (Nicholson, 1991).

Evidence for the role of self-esteem in psychological well-being is presented below, with particular consideration of research with people with learning disabilities. It is important initially to consider definitions: the concept tends to be loosely-defined, leading to methodological inconsistencies.

### **1.1: Definitions**

#### *Self-concept*

Self-concept is defined as "a global evaluation made about one's own personality" (Bruno, 1986). Bruno considered it to be formed from the subjective evaluations we make of our behavioural traits, whereas Mead (1934) considered self-concept to be ultimately a social construction, being a "reflection of the opinions and attitudes communicated by significant others" (Harre & Lamb, 1983). Reber (1985) defined it as "as complete and thorough a description [of oneself] as it is possible to give", without any emphasis on evaluation.

## *Self-esteem*

Self-esteem is effectively the evaluative aspect of one's self-concept in relation to others - "how high or low one ranks oneself in terms of subjectively perceived personal status" (Bruno, 1986), or "the extent to which the individual believes himself or herself to be significant" (Harre & Lamb, 1983).

Robson (1989) devised a useful definition derived from a consideration of the work of Coopersmith (1967), Rosenberg (1965), Beck (1967) and Abramson *et al.* (1978) as follows:

"The sense of contentment and self-acceptance that results from a person's appraisal of his own worth, significance, attractiveness, competence and ability to satisfy his aspirations."

### **1.2: Research into the relationship between self-esteem and psychological well-being.**

Recognition of the role of self-esteem in psychological well-being is evident in disparate areas of research. Coopersmith's seminal work into the antecedents of self-esteem took as its basis "the widely held belief that self-esteem is significantly associated with personal satisfaction and effective functioning" (Coopersmith, 1967).

Attempts to preserve or enhance self-esteem have been cited as central themes in relation to adaptation and successful coping with a number of disorders, such as breast cancer (Taylor, 1983; cited in Pitts, 1991), diabetes (May, 1991) and depression in young mothers (Newton, 1992). Beck's cognitive theory of depression (Beck, 1967; Beck, Rush, Shaw & Emery, 1979) proposes that low self-esteem is a

common factor in vulnerability to depression, though Brown & Harris (1989) acknowledged that research methods to date have not been sensitive enough to test out the proportional relationships between these factors. One pervasive difficulty is ascertaining whether self-esteem plays a causal or mediating role in determining psychological health, or whether the relationships are simply correlational. In a review of research into depression, Brewin (1985) proposed that the evidence to date indicates that low self-esteem may be a consequence of the disorder and indicative of positive or negative coping styles. In a recent study, Button, Sonuga-Barke, Davies & Thompson, (1996) found that low self-esteem predicted increased likelihood of the development of an eating disorder in adolescent girls, but the relationship has not been demonstrated as causal.

### **1.3 Self-esteem Measurement in Clinical Settings**

Measures of self-esteem are commonly employed in clinical settings (e.g. Robson, 1989). This again testifies to the importance placed on self-esteem when considering psychological well-being. A number of measures of self-esteem have been developed for use with adults and children, such as the Coopersmith Self-Esteem Inventory (Coopersmith, 1967) and the McDaniels-Piers Young Children's Self-Concept Scale (McDaniels & Piers, 1973).

A number of difficulties in the use of these measures are outlined in the literature. Of most concern is assessing precisely what is being measured. This uncertainty arises both from problems of definition (self-esteem as the subjective evaluation of one's own value is open to many interpretations) and from the

recognition that self-evaluation may occur predominantly at a pre-conscious level (Harre & Lamb, 1983). Attempts to intellectualise these pre-verbal constructs are fraught with problems.

Standardised psychometric measures of self-concept are necessarily "external" to the subject, failing to give insight into their internal mental processes (Jahoda, Markova & Cattermole, 1988) and imposing the particular constructs considered important by the researcher rather than allowing for individual differences.

Robson (1989) highlighted the difficulties in attempts to quantify abstract notions. For example, theorists such as Rosenberg (1965), Coopersmith (1967) and Beck (1967) (cited in Robson, 1989) individually proposed the development of self-esteem based on beliefs stemming from self-evaluation of character, abilities and behaviour, which result from earlier experiences. Robson suggested that the multidimensional nature of self-esteem means that deficits in some areas could be counterbalanced by excesses in others. It may therefore be more meaningful to analyse these subordinate elements contributing to self-esteem rather than using global self-esteem scores. This proposition, however, leads to further complications in assessing the validity of each element as a component of self-esteem, and again the possibility of overlooking factors which are not salient to individual researchers.

Despite these caveats, Robson (1989) outlined three reasons to continue with attempts to devise measures of self-esteem:

(I) Logically, there must be a link between a person's opinion of him/herself and his concern about the consequences of his actions, so that it should be possible to predict certain aspects of behaviour from an accurate estimate of self-esteem.

(ii) A literature review demonstrates the association of low self-esteem with many “undesirable traits, symptoms or behaviour” (as indicated in Section 1.2). If there is evidence of a causal or maintaining role, it is important to investigate treatment implications.

(iii) The subjective opinion of many therapists is that improvement in self-esteem is an important part of treatment, and this should be tested empirically.

#### **1.4: Research into self-esteem with people with learning disabilities**

The problems of verbalising abstract, pre-conscious concepts are likely to be compounded for clients with intellectual impairment and often concurrent communication deficits. A number of researchers have attempted to assess self-esteem in people with learning disabilities. Unfortunately, few researchers have adopted the same approach, and there are differences in focus between self-concept and self-esteem, so that opportunities for cross-study comparisons are limited. Several studies employ small numbers of participants, again reducing the generalisability of results.

A potentially important “subordinate element” (Robson, 1989) of self-esteem for people with learning disabilities is their perception of themselves as “disabled”, “different” or “stigmatised”. Some research has attempted to assess the impact of perception of stigma with people with learning disabilities. There are similarities with other stigmatised groups such as minority ethnic communities, people with physical disabilities, people with HIV/AIDS. It is not possible to review the literature on self-esteem with these and other minority groups here, but it is important in the longer-

term to establish which factors or experiences are common to the experience of stigmatisation and which are particular to learning disabilities.

The main studies into self-esteem in people with learning disabilities are reviewed in chronological order.

#### **1.4.1 Edgerton (1967)**

Edgerton conducted an anthropological study of 48 men and women who had been discharged from a large hospital to live in the community. He produced a wealth of qualitative information about their experiences and self-views, based largely on unstructured interviews and "participant observation", i.e. accompanying participants in their daily lives over a considerable time-period. The study elicited in particular people's subjective experiences of stigma, and Edgerton proposed that people with learning disabilities "cannot both believe that they are mentally retarded and still maintain their self-esteem". He observed their use of the defences of "passing" (attempting to be seen as "normal") and denial.

The study is a fascinating and thorough examination of the participants' experiences, and it successfully placed the study of learning disabilities in "the social and cultural webs within which it takes on its meaning and becomes a problem" (Edgerton, 1967). The method used, however, is time-consuming and unstructured, thus limiting opportunities for replication and comparison. The findings may be particular to the experience of leaving institutional care in that decade - subsequent changes in social policy may mean that less extreme perceptions of stigma would be found in an updated study. Edgerton and his colleagues (Edgerton & Bercovici, 1976; Edgerton, Bollinger & Herr, 1984) were able to follow-up a



proportion of their participants over twenty years and did find improvements over time.

#### **1.4.2 Coleman (1983)**

In a study with schoolchildren, Coleman found that both learning-disabled and non-disabled children showed more negative self-concept in classes containing groups of generally greater ability. Both groups, however, had comparable and higher levels of self-concept in special education programmes which placed students of similar abilities in the same class. This study suggests, perhaps unexpectedly, that segregated classes have a positive impact on self-esteem due to the opportunity for favourable social comparisons, though the mechanism of this effect requires further analysis.

#### **1.4.3 Gibbons (1985)**

Gibbons interviewed a large sample ( $N=123$ ) of people with learning disabilities. He used photographs of people, half of whom were labelled "retarded", and asked participants questions about these people. The "retarded" person was seen more negatively in terms of social behaviour. In a second study, 106 of the participants were asked the same questions about themselves. They rated themselves more highly than the targets (regardless of the label) on most measures.

Gibbons proposed that the results provide some evidence of downward comparisons with other people with learning disabilities. Results are weakened by the lack of tests of validity or reliability and the two- to twelve-month gap between the first and second study. In addition, each participant only rated target figures of

the opposite sex, so results may be confounded by cross-gender effects. Self-concept was measured only in terms of friendliness, smartness, social acceptance (ie. perceived likelihood of going on dates and getting married) and physical attractiveness.

#### **1.4.4 Zetlin, Heriot & Turner (1985)**

Zetlin *et al.* conducted a study analysing the response styles of 46 adults with learning disabilities using two scales standardised for the general population, the Piers-Harris (1964) and the Coopersmith (1967) self-esteem scales. Participants were seen for a series of half-hour sessions for verbal administration of the measures. Tape-recordings of the sessions were then analysed for initial and general responses. They found that over half of the initial responses were ambiguous and difficult to score. They proposed that standardised probing of items may be necessary to ensure more "scorable" responses, or provision of a scaled selection of choices for qualifying responses. They highlighted the need for "more systematic research on the design as well as administration and scoring of these measures".

Again, there are specific difficulties with the design of the study. The questionnaires used are not standardised for this population, and the use of probes may have led to the impression for some clients that they had not yet given the *correct* response. In addition, each participant saw two different researchers for the administration of different measures, which, while possibly reducing "examiner effects", may have added to the unfamiliarity of the testing situation.

#### **1.4.5 Oliver (1986)**

Oliver presented a case study in which he used a repertory grid technique with a 14-year-old girl with Downs' Syndrome. This involved describing herself and seven other people and ranking each person on the constructs generated by the descriptions. The repertory grid showed that the client ranked herself as different from other children with learning disabilities and more like her "ideal-self". While the study demonstrates the applicability of the approach, generalisations cannot be drawn from one case. Self-concept is measured solely in relation to social relationships.

Repertory grids were also used by Spindler-Barton, Walton & Rowe (1976) with 26 learning disabled people, but they did not focus on self-concept or self-esteem. A further study into self-esteem using the repertory grid approach is currently underway (Sandhu, personal communication).

#### **1.4.6 Jahoda *et al.* (1988)**

This study aimed to evaluate the social constructionist theory of self-perception (Mead, 1934), which asserts that self-concept is largely determined by the way one is treated by significant others. Jahoda *et al.* used semi-structured interviews with twelve people with mild learning disabilities, their mothers and a keyworker at their adult training centre (ATC). They found that three participants considered themselves to be "essentially different" from non-disabled people, and nine considered themselves "essentially the same". All mothers considered their children to be "essentially different" from non-disabled people. Jahoda *et al.* interpreted the findings as refuting the social constructionist perspective, as clients did not

necessarily adopt their parents' perspective. The study does not allow exploration of the impact of the views of alternative "significant others" through school and ATCs. Self-advocacy movements and "consciousness-raising" (Szivos & Travers, 1988; Szivos and Griffiths, 1990) may lead to exposure to more favoured and explicit messages of "sameness" within these settings.

The sample is too small to draw firm conclusions, but the study did link consideration of the impact of participants' awareness of stigma and the impact of this on self-esteem at an emotional as well as a cognitive level.

#### **1.4.7 Benson & Ivins (1992)**

In a study exploring the relationship between anger, depression and self-concept in adults with learning disabilities, Benson & Ivins again used a measure developed for a child population, the McDaniels-Piers Young Children's Self-Concept Scale (McDániels & Piers, 1973). They used a large sample ( $N=130$ ) and found significant positive correlations between self- and informant-report measures of self-concept and depression. They reported that participants with high scores of depression had a lower self-concept, and that participants with mild learning disabilities reported greater anger than those in the moderate/severe range. They hypothesised that people with less severe learning disabilities may be more aware of and frustrated by their limitations.

While the sample is large, results must again be treated with caution, as they are based on correlations between three measures which have not been validated for this population and were in fact developed for use with children. The self-concept scale requires yes/no responses, the reliability of which has been questioned in

other research (Sigelman, Budd, Winer, Schoenrock & Martin, 1982; Zetlin *et al.*, 1985).

#### **1.4.8 Szivos-Bach (1993)**

Szivos-Bach attempted to link research into self-esteem and stigma to consider self-esteem within a societal context. Goffman (1963) proposed that perception of a negatively valued discrepancy between actual and virtual identity (how one is and how one is expected to be) is fundamental to the subjective experience of stigma, ie. individuals perceive stigma via negative reflected appraisals. Edgerton (1967) and Jahoda *et al.* (1988) had found evidence of some participants' awareness of themselves as "different" or "retarded".

The definitions of self-esteem provided above (Section 1.1) also highlight the importance of the *social* context in self-evaluations. Social comparisons theory (Festinger, 1953; Suls, 1991) argues for the role of social comparisons in recognising one's "status" in relation to others.

Szivos-Bach (1993) highlighted the anomaly in predictions made by these theories in relation to the philosophy of "normalisation" and integrating people with learning disabilities into community facilities. Mainstreaming may improve self-esteem because people are receiving positive reflected appraisals as to their "normality", or alternatively may worsen self-esteem because people will make unfavourable social comparisons with non-handicapped reference groups, as was indicated by Coleman's (1983) study.

Szivos-Bach developed measures of social comparisons, perception of stigma and aspirations/expectations in order to assess these aspects of self-esteem and stigma.

1. The *social comparisons test* used 24 items from other self-esteem questionnaires, rated by participants with reference to themselves and four comparison figures; friend (with learning disabilities), other (without learning disabilities), sibling and ideal self.

2. The *stigma questionnaire* involved ten questions drawn from other studies and from talking to people with learning disabilities. Responses were rated on a five-point scale, with participants invited to "talk around" each item before deciding on a score.

3. The *aspirations and expectations test* drew on Edgerton's (1967) findings about what people discharged from institutions aspired to, representing generally valued milestones. Participants rated whether they would like to do these things in the future and whether they would be able to do them. A large discrepancy score indicated the subject believed him/herself unlikely to achieve his/her aspirations.

Szivos-Bach administered the measures to 50 young people with learning disabilities, all of whom attended colleges of further education. She found that the mean social comparisons scores for "self", "friend" and "sibling" were similar, but scores for "other" and "ideal" were significantly higher. There was a consistent pattern of correlations with the stigma score in that students with the highest "self" and "ideal" scores showed the least awareness of stigma, and students with lower self scores perceived the most stigma. The aspiration score was significantly

correlated with the ideal score, and the aspirations-expectations discrepancy was negatively correlated with the stigma score.

The measures devised by Szivos-Bach appear to have promise as research tools for use with this population, in that she reported no difficulties of comprehension for the tests and the individual measures correlated with each other in the predicted direction. She did not, however, assess construct validity by comparison with existing standardised measures, or reliability over time. The subject sample consisted of young, relatively able adults with learning disabilities, and it would be important to assess the measures further with a more heterogeneous sample.

This review of research into the self-esteem of people with learning disabilities highlights the diversity of approaches adopted and the lack of attention paid to developing a valid and reliable measure. Researchers have been keen to discover the impact of self-image on this stigmatised group and have neglected first to develop appropriate tools for their exploration.

There are particular difficulties in conducting standardised and quantitative research with this population, some of which are evident in these studies. It is important to consider these methodological difficulties in more detail to understand why the diversity of approaches to self-esteem measurement has arisen, and to consider where to go from here.

### **1.5: Research methodology**

Research focussing on people with learning disabilities has often centred directly on the experience of families and carers, or used information from carer questionnaires and direct observation to infer an understanding of clients and their experiences. A minority of studies have relied on clients themselves to provide data (eg. Edgerton, 1967). There has been some shift in attitudes in recent years: Simons *et al.* (1989) cited over 20 British papers in the past five years which involved opinions expressed by clients with learning disabilities, whereas Richards (1984) had identified only 5 such studies in the previous twenty years.

While services increasingly agree that clients should have a voice in determining how their lives progress, numerous difficulties arise in attempts to elicit this voice. An initial problem is that "people with learning disabilities" encompasses a large and heterogeneous group. It is probably not realistic to expect a single approach to produce reliable and valid data for all members of this group. A proportion are people with severe and profound learning disabilities, who may have little or no speech or communicative abilities. Assessments e.g. of their experience of quality of life must at present rely on observation and carer views. Even within samples of people with mild or moderate learning disabilities, certain approaches may be more appropriate for particular subgroups than others. For example, Atkinson (1985) asked participants to keep diaries as part of her study: some provided detailed accounts while others produced little.



Studies eliciting the views of clients have relied almost exclusively on verbal methods (Simons *et al.*, 1989). Some researchers have explored which methods may elicit meaningful data for people with mild or moderate learning disabilities, and a brief resume is presented below.

### **1.5.1 Participant observation and unstructured interviews**

Edgerton (1967; Edgerton & Bercovici, 1976; Edgerton *et al.*, 1984) used a "loosely structured schedule" as described above (Section 1.4.1), developing relationships with participants before commencing any interviews, and combining information with extensive participant observation. The result of this was a wealth of qualitative information about the concerns and self-concept of these participants.

The set of studies provides valuable longitudinal information, but relates to a group of very able clients, so that conclusions cannot necessarily be applied to less independent clients. It also uses a demanding, time-consuming approach which has rarely been replicated, though Cattermole, Jahoda & Markova (1987) (cited in Simons *et al.*, 1989) and Atkinson (1985) also used participant observation and unstructured interviewing in studies exploring the transition of people from hospitals into more independent living situations.

### **1.5.2 Participative methods**

Walmsley (1991) reported a small project investigating the meaning of adulthood for five people with learning disabilities. Her research was based on feminist principles which address the power imbalance inherent in much research: "who controls the research in terms of framing the questions, interpreting meanings and producing the

results?" (Walmsley, 1991). Data were gathered by unstructured interviews, but particular emphasis was placed on maximising the involvement of participants in setting the research agenda and debating the findings. Although the sample was small and results are qualitative, Walmsley described the process as "empowering" and potentially widely applicable.

### **1.5.3 Comparison of question formats**

A number of authors have explored the use of different question formats. Sigelman *et al.* (1982) proposed that acquiescence - "the tendency to respond affirmatively regardless of a question's content" - and variation in response according to how a question is worded or structured (open-ended versus "closed") are particular dangers when conducting research with people with learning disabilities. They developed interview schedules which asked questions on the same topics in different formats: open-ended questions, open-ended questions with probes ("what else?" until the client stopped answering), yes-no questions and verbal and pictorial multiple-choice. Three samples were tested: children with learning disabilities living in the community and in institutions, and adults living in institutional settings. The topics chosen were factual (eg. "do you play any indoor games?"). Sigelman *et al.* concluded that open-ended questions were more valid than yes-no questions but limited responsiveness, while verbal and pictorial multiple choice "increased responsiveness without lowering agreement with informants and without generating systematic response biases".

One difficulty with the research is the reliance on information from familiar adults (parents or carers) to assess validity of responses. The subjective views of

others on items such as how much the subject liked their home cannot be assumed to be more "true" than the client's own expressed opinion!

Dagnan & Ruddick (1995) investigated the use of analogue scales and personal questionnaires as part of a consumer satisfaction survey of people with learning disabilities. They found that most of their 29 participants could use both approaches consistently, with a tendency for the personal questionnaire to be more suitable for people with higher receptive language abilities.

Chapman & Oakes (1995) also piloted a methodology for asking clients their views on psychological services. They used either/or questions, multiple choice and open-ended questions. They found that all question types were easily answered, though either/or questions limited the depth of information gained. They recommended using a combination of multiple-choice and open-ended questions "to obtain the most valid and useful information and to reduce the rather structured and interrogative nature of the interview". Their results were based on a small sample ( $N=12$ ) of verbally able clients.

#### ***1.5.4 Summary of implications***

The results of these studies indicate that people with mild/moderate learning disabilities and verbal abilities are able to give meaningful responses in well-designed studies. Qualitative methods have been more popular due to the perceived unreliability of clients' responses to closed questions, but more careful research analysis has found that quantitative data can be successfully elicited using open-ended or multiple-choice questions.

### **1.6: Rationale for the current study**

There are a number of reasons for persisting with the attempt to develop a reliable method of assessing self-perception for this group.

1. Current developments in social policy with regard to people with learning disabilities. These cannot be explored in detail here, but implicit within the philosophy of social role valorisation or normalisation (Wolfensberger, 1972; 1983) is the tenet that being in culturally valued roles is psychologically healthy and therefore promotes positive self-esteem (Emerson, 1992). It seems important that policies should be tested in terms of their impact on self-esteem along with other aspects of quality of life. In a recent review of 71 studies documenting the effects of deinstitutionalisation in the UK (Emerson & Hatton, 1996), no mention was made of the impact on clients' self-esteem, and only seven of the studies reviewed assessed users' satisfaction either with the services they were receiving or with life in general.

2. From a social psychological perspective, it is important to develop an understanding of the subjective experiences of people with learning disabilities. This would add weight to theories of the impact of marginalisation on minority groups, and of the impact at a personal level of being labelled "learning disabled": there are conflicting views on the utility of labels for children with developmental disorders (Lask, 1996). It is acknowledged that "people with learning disabilities" encompasses a large and heterogeneous group: systematic research into self-esteem

might highlight some components of self-perception which are common factors for this group. Appropriate interventions may then be possible to remedy deleterious factors and promote beneficial ones.

3. Clinical applications. In a number of mental health service settings, measures of self-esteem or self-concept are used regularly to assess presentation or change over time. At present, there are no such standardised measures for use with people with learning disabilities.

4. Research. The development of a standardised measure of self-esteem would add an important research tool to the current short supply of standardised measures for people with learning disabilities.

5. Empowerment. At present, the majority of research studies and strategies for service planning focus on the views and experiences of families or carers rather than clients (Simons *et al.*, 1989). There is a developing trend for services to seek clients' own views (Elcombe, 1993; Dagnan & Ruddick, 1995). It can be hypothesised that clients will feel empowered by the interest shown in their own views and subjective experiences, if these are sought in a sensitive manner.

From the review of research into self-esteem (Section 1.4), it seems that one of the most promising approaches would be to assess further the standardisation of Szivos-Bach's (1993) set of measures. It was decided to focus on assessing the test-retest reliability and construct validity of these measures of self-esteem, perception of stigma and aspirations-expectations. If valid, this set of measures incorporates a number of important considerations for a measure of self-esteem:

- a. They were specifically designed for use with people with learning disabilities and are therefore “user-friendly”.
- b. The administration and scoring takes into account the recommendations arising from research into methodological difficulties in research with this population.
- c. The measures combine assessment of more than one facet of the factors thought to influence self-esteem. Consideration of the relationship between social comparisons and the perception of stigma is of particular importance in attempting to understand the experiences of people with learning disabilities.
- d. The standardised measure should provide a straightforward screening and monitoring instrument for use in clinical settings.

The measure has the potential to fit Robson’s (1989) criteria that

“To be useful in clinical research, a scale for measuring self-esteem must be easily comprehensible to patients and quick to complete, and demonstrate satisfactory psychometric properties without sacrificing intuitive breadth of meaning.”

### ***1.6.1. Concepts of validity and reliability***

The development of standardised questionnaires takes time and usually series of research studies, so that the process can only begin to be addressed here. Standardisation requires the adjustment of measures using tests of reliability and

validity to eliminate items until "it is useful as a measure of the population it is targetted at, and will enable us to confidently compare individuals" (Coolican, 1991).

A reliable measure is accurate in terms of producing the same results on different occasions. Assessment of external reliability therefore involves test-retest with the same participants.

Validity is the sense in which a test measures what it purports to measure, e.g. a self-esteem questionnaire measures self-esteem rather than psychological well-being. As measures are usually developed from a theoretical perspective, validity is assessed with reference to predictions from that theory. Bellack & Hersen (1984) proposed that construct validation is "a gradual incremental process as evidence builds towards a coherent and persuasive case for linking the measure and the construct".

The approaches to assessing construct validity adopted here are convergent validity, i.e. the measure of self-esteem should correlate well with other measures of the same construct, and discriminant validity, i.e. the measure of self-esteem should not correlate well with measures of other constructs. For more detailed consideration of approaches to validation, the reader is referred to Coolican (1991).

### **1.6.2 Methodology**

Attempts to assess the construct validity of measures for people with learning disabilities can be fraught, as there is a paucity of valid comparison measures for this population (Sturmey, Reed & Corbett, 1991). Two measures were identified which had been adapted for use with this population and which measured attributes likely to be associated with level of self-esteem (convergent validity): the Zung

Depression Scale (Zung, 1965), identifying symptoms of depression, and the Social Performance Survey Schedule (Lowe & Cautela, 1978), indicating the presence of appropriate social skills.

A number of researchers have proposed the need to consider subjective well-being in addition to indicators of psychological ill-health. Watson, Clark & Tellegen (1988) reported that dimensions of experience such as enthusiasm-lethargy and calmness-anger/fear are not necessarily opposites (negatively correlated). Scales such as the Positive and Negative Affect Schedule (PANAS, Watson *et al.*, 1988) and the Satisfaction with Life Scale (Deiner, Emmons, Larsen & Griffin, 1985) have been developed for use with the general population. As no equivalent scale is available for use with people with learning disabilities, it was decided to investigate the association with self-esteem in a preliminary way, developing a short scale of emotional well-being based on those existing measures.

In addition, certain lifestyle factors may be expected to correlate with positive or negative self-esteem. Those identified for the purposes of this study were place of residence (eg. people living independently may have higher self-esteem than people in staffed group homes), work experience (eg. people currently involved in work placements may have higher self-esteem than people who had never worked), and additional physical disabilities, as research indicates that the presence of physical disabilities in the *non-learning* disabled is related to low self-esteem (Lawrence, 1991).



## **1.7: Hypotheses**

### **H1:**

The social comparisons test, stigma questionnaire and aspirations-expectations test (Szivos-Bach, 1993) are reliable measures over time.

### **H2:**

High self-esteem as measured on the social comparisons test will correlate with low ratings of depression (measured on the Zung Depression Scale, Zung, 1965) and with good social and interpersonal skills (measured on the Social Performance Survey Schedule, SPSS, Lowe & Cautela, 1978). Low self-esteem will correlate with high depression scores and poor social and interpersonal skills.

Self-esteem will not correlate with gender, age or IQ (measured by performance on the British Picture Vocabulary Scale, Dunn, Dunn & Whetton, 1982).

### **H3:**

High scores on the stigma questionnaire (ie. participants perceiving high levels of stigmatisation) will correlate significantly with high scores on the Zung Depression Scale, and with low scores on the SPSS. Low perception of stigma will correlate with low depression scores and high scores on the SPSS.

Stigma scores will not be related significantly to gender, IQ or age.

H4:

Small discrepancies between the aspirations and expectations scores, indicating that participants expect to achieve their ambitions, will correlate significantly with low scores on the Zung depression scale and high scores on the SPSS. Large discrepancies, indicating that participants do not expect to achieve their ambitions, will correlate significantly with high depression scores and low SPSS scores.

H5:

Within the social comparisons test, participants will rate themselves (Self score) as similar to their friends (i.e. no significant difference). The Other and Ideal scores will be significantly higher than the Self score.

H6:

High self-esteem will correlate with low scores on the perception of stigma scale and with small discrepancies between the aspirations and expectations scores.

H7:

High self-esteem will correlate with high scores on the measure of emotional well-being. Low scores of emotional well-being will correlate with high scores on the stigma questionnaire and large discrepancies between aspirations and expectations scores..

## **Section 2: METHOD**

### **2.1: Participants**

The study aimed to recruit 30 to 50 participants with mild or moderate learning disabilities, both male and female and between the ages of 18 and 65. Specification of clients' abilities was left open in order to recruit participants with a range of abilities: the only limitations were that they should have:

1. Verbal abilities using spoken English to respond to open-ended questions in a form other than a yes/no response, or
2. If non-verbal, able to comprehend speech and to allocate choices on a three- and five-point scale.

The interview procedure was designed to assess further participants' ability to respond appropriately and therefore their suitability for inclusion in the study after initial recruitment.

Participants were recruited from two social services day centres for adults with learning disabilities. The centres are based in separate towns within the same county, and so share an overall management structure and service philosophy. Each centre is relatively large, with a register of 80 to 120 clients attending on a five-day or sessional basis.

Both centres offer a range of group activities, based within the centres and in local community facilities such as the college of further education. A number of clients are engaged in work experience projects as part of their weekly timetable.

## **2.2: Design**

The study was designed as a cross-sectional questionnaire survey to test the validity of Szivos-Bach's (1993) measures of self-esteem and stigma by correlational methods. Measures were repeated at a two to three-month interval to assess test-retest reliability.

## **2.3: Measures**

### ***2.3.1 Demographic Data*** [Appendix 1]

Information collected included participants' age, gender, place of residence (eg. independent, parental home, staffed group home), current or previous work experience and whether they had an additional physical disability.

Demographic data also included administration of the British Picture Vocabulary Scales (BPVS, Dunn *et al.*, 1982). The BPVS gives a measure of receptive language skills and was used by Szivos-Bach (1993) to provide an indication of IQ.

### ***2.3.2. Social Comparisons Test*** (Szivos-Bach, 1993)

The social comparisons test (items shown in Table 2.1) comprises 24 items chosen from different self-esteem questionnaires to cover the dimensions identified by Coopersmith (1967) as important to self-esteem. These dimensions are:

Power/significance (the ability to influence and be esteemed by others).

Virtue/values (adherence to social norms and virtues).

Competence (abilities in socially valued areas).

The items are rated on a five-point scale, made concrete by use of a pictorial ladder with person-shaped counters for each comparison figure. Higher rungs on the ladder indicate increasing levels of agreement with the item. Verbal labels are used for each ladder rung as an aid for understanding; from the top down these verbal labels are "all the time", "most of the time", "quite a lot of the time", "a bit of the time" and "none of the time".

Each item is rated with reference to Self, Friend (someone with learning disabilities), Other (someone without learning disabilities) and Ideal (how you would like to be), and negative items are reverse-scored. The test therefore produces four main scores (total scores for Self, Friend, Other and Ideal), of which the Self score is the measure of self-esteem.

Table 2.1: Items in the Social Comparisons Test

<i>Coopersmith's Dimensions (1967)</i>	<i>Positive</i>	<i>Negative</i>
<i>Power / Significance</i>	I have good ideas	I get nervous
	I am good at making friends	People forget I'm there
	I get on with the opposite sex	I am lonely
	I have fun with friends	I get picked on
<i>Virtue / Values</i>	I look nice	I cause trouble
	I do as I am told	I am lazy
	I am helpful to others	I tell lies
	I am happy	I am unkind to others
<i>Competence</i>	I am good at work	I give up easily
	I am good at making things with my hands	I am slow at work
	I can speak well in front of others	I make a mess of things I try
	I am good at sport	I forget things

The measure has not been assessed for construct validity or reliability. Szivos-Bach (1993) reported item-total correlations between .28 and .70 with a scale alpha of .87, indicating acceptable scale homogeneity.

In her original study, Szivos-Bach (1993) included a fourth comparison figure, Sibling. This figure was omitted for the purposes of this study for a number of reasons.

1. The mean scores for Friend and Sibling did not differ, so that it may be sufficient to include just one of these measures to achieve meaningful results.
2. This study entailed a more complicated design with the addition of extra measures. Interviews would therefore be more time-consuming and potentially tiring for participants: it was felt that the omission of one comparison figure may reduce these demands to a more reasonable level without compromising the overall integrity of the research.
3. The sample for this study was expected to be older than in Szivos-Bach's study. It was therefore hypothesised that participants would have less contact with their siblings and they may therefore have less relevance as comparison figures.

### **2.3.3 Stigma Questionnaire** (Szivos-Bach, 1993)

The stigma questionnaire comprises ten items (see Table 2.2) drawn from a number of sources: items identified by parents of handicapped children (Levinson & Starling, 1981); items which identified between handicapped and non-handicapped young adults (Kuh, 1985); items identified by Szivos-Bach in discussion with people with

learning disabilities, and one item from the Piers-Harris self-esteem questionnaire (1964) which expressed feelings of being "different" which are negatively valued.

Table 2.2: Items in the Stigma questionnaire

<i>Factor</i>	<i>Items</i>
<i>I. Feeling Different</i>	1. My family is disappointed in me 2. People treat me like a child 3. I wish I were someone different 8. Other people treat me oddly
<i>II. Anxiety</i>	4. I get teased or made fun of 5. I am uncomfortable in the presence of strangers 6. In groups I feel the odd one out
<i>III. Poor Ingroup Concept</i>	7. I worry about what other people think of me 9. I hate telling people I come from this place 10. I hate going out in a group with people from here

The questionnaire is deemed to have face validity in that the items reflect feelings of being "different" rather than simply negative items such as may appear on a self-concept measure (Szivos-Bach, 1993). Item-total correlations of the scale ranged from .34 to .62 with a scale alpha of .81, indicating acceptable scale homogeneity. The construct validity and test-retest reliability of the scale have not been assessed.

A Principle Components Factor Analysis revealed one main factor. A Varimax rotation revealed three factors labelled Feeling Different, Anxiety and Poor Ingroup Concept, shown in Table 2.2 (Szivos-Bach, 1993).

### 2.3.4 Aspirations-Expectations Test (Szivos-Bach, 1993)

The aspirations-expectations test comprises eight items drawn from Edgerton's (1967) findings about his participants' aspirations. Szivos-Bach (1993) surmised that these represent normative valued milestones for most people, and they therefore have face validity. The items are shown in Table 2.3.

Participants are asked if they would like to do these things in the future (aspirations) and if they would be able to do them (expectations). Items are scored on a three-point scale:

*Aspirations:* I would like to (3); I don't know (2); I would not like to (1).

*Expectations:* I will be able to (3); I don't know (2); I will not be able to (1).

Table 2.3: Items in the Aspirations-Expectations test

- 
1. Drive a car or motorbike
  2. Have a girl/boyfriend
  3. Have a girl/boyfriend "outside"
  4. Get married
  5. Have children
  6. Get a job (specify)
  7. Earn a lot of money (specify)
  8. Live somewhere different (specify)
- 

The scores are summed and a discrepancy score is calculated by subtracting the expectations score from the aspirations score. A large discrepancy score indicates that the participant believes him or herself to be unlikely to achieve his/her ambitions in life.



Szivos-Bach (1993; Szivos, 1990) did not report any tests of internal reliability for this measure.

### **2.3.5 Zung Depression Scale** (Zung, 1965) [Appendix 2]

The Zung depression scale is a twenty-item self-report measure designed to assess the presence of depression as a psychiatric disorder. It was shown to differentiate between participants before and after treatment (Zung, 1965).

The Zung depression scale has been adapted for use with learning disabled adults (Kazdin, Matson & Senatore, 1983; Helsel & Matson, 1988). Kazdin *et al.* (1983) demonstrated that the adapted Zung depression scale discriminated between depressed and nondepressed patients ( $M=38.3$ ,  $30.9$  respectively,  $F=4.07$ ,  $d.f.=1$ ,  $104$ ,  $p<.05$ ). The scores correlated consistently with other self-rated and informant-rated measures of depression (e.g. Beck Depression Inventory, Hamilton Depression Scale and Psychopathology Instrument for Mentally Retarded Adults, PIMRA).

In their adaptation of the Zung scale, Kazdin *et al.* (1983) simplified the language, used an interview format with participants and used the visual aid of a bar graph to aid participants in using the four-point Likert scale for responses.

In a British study, Lindsay & Michie (1988) reported adaptations to the Zung self-rating *anxiety* scale for use with people with learning disabilities. Their adaptation involved using an interview format and rephrasing or rewording items which were difficult to understand, using local dialect if necessary. They tested different response formats and found the most reliable to be asking the participant whether a symptom was present or absent (yes/no). Other papers report similar use

of an adapted Zung *depression* scale (Lindsay, Howells & Pitcaithly, 1993; Lindsay, Michie, Baty, Smith & Miller, 1994), but there is no published documentation of their precise adaptations (Lindsay, personal communication). The depression scores reported in these studies, however, are not consistent with use of a two-point yes/no scoring system (e.g.  $M=37.87$ ,  $SD=10.04$ , Lindsay *et al.*, 1994). It seems that these authors, like Kazdin *et al.* (1983) were able to employ the standard four-point Likert scale.

In this study, the four-point scale was used (labels being "a little of the time, some of the time, quite a lot of the time and most of the time"), with the visual aid of a bar chart, the bars increasing in size the more the symptom was experienced. The standard questions were used, with additional rewording (indicated in Appendix 2) if necessary, and the interviewer talked around each question with participants to check their comprehension. This approach fitted with the recommendations of Lindsay & Michie (1988) that

"it is essential to have a test which is accurately understood by clients, and if a small degree of standardisation must be lost because of this, then it cannot be avoided".

### **2.3.6 Measure of emotional well-being**

A five-item questionnaire was used to measure subjective well-being and satisfaction with life. Development of the questionnaire is described further in Section 2.4.1 (Pilot). Items were adapted from the PANAS (Positive and Negative Affect Schedule) scales (Watson *et al.*, 1988) and the Satisfaction with Life Scale

(Deiner *et al.*, 1985). See Appendix 3 for these measures and the 6-item questionnaire used in the pilot study.

The final version is presented in Table 2.4. Item one was included as a global measure of well-being and as a check on validity to contrast with item one on the Zung Depression scale ("I feel downhearted and blue/ I feel sad"). Items were scored on a four-point Likert scale as for the Zung Depression Scale.

Table 2.4: Items in the measure of emotional well-being.

- 
1. I feel happy.
  2. I feel confident and sure of myself.  
(I feel I can do lots of things.)
  3. I find it easy to concentrate.  
(I don't get put off what I'm doing.)
  4. If I could live my life over again, I would not  
change things.
  5. I feel enthusiastic.  
(There are things that excite me that I really like.)
- 

**2.3.7 Social Performance Survey Schedule (SPSS)** (Lowe & Cautela, 1978; adapted by Matson, Helsel, Bellack & Senatore, 1983) [Appendix 4]

In its original form, the Social Performance Survey Schedule (Lowe & Cautela, 1978) consisted of 100 descriptions of social behaviour (fifty positive and fifty negative) rated on a five-point Likert scale. The instrument was designed as a self-rating measure to assess overall social performance. Lowe & Cautela reported high internal consistency (Cronbach's alpha .87) and test-retest reliability (Pearson's correlation .86).

The measure was adapted for use with adults with learning disabilities by Matson *et al.* (1983) in a two-stage study. Initially, pairs of staff rated 22 adults with learning disabilities in order to assess which items could be accurately rated. Secondly, the 57 strongest items were used by a familiar staff member to rate 207 adults with learning disabilities, to establish factors within the scale.

In a further study, Helsel & Matson (1988) attempted to evaluate the interrelationship between depression, intellectual functioning, receptive language and social skills. For the latter, they employed a self-report version of the 57-item SPSS, using a three-point Likert scale, in addition to an informant-report version completed on a third of their participants. They did not report significant correlations between these measures and have not reported any data on the reliability and validity of the adapted self-rating scale.

For the purposes of this study, the 57-item other-report measure was chosen. In addition to the stronger evidence of standardisation for this measure in the literature, it was also likely that using the self-report version would impose unacceptable demands on the participants themselves. Increasing further the number of measures used with them would be likely to cause fatigue, disinterest and would invalidate responses.

Matson *et al.* (1983) reported data on inter-rater reliability with just 22 participants (mean  $r=.57$ , range .30-.82), and did not measure construct validity by correlations with any other measures. Helsel & Matson (1988) reported significant correlations for the *self-report* SPSS with the Zung depression scale. Due to these incomplete results, the SPSS was here completed independently by two staff

familiar with each subject in this study. Inter-rater reliability could then be assessed rather than assumed before analysing correlations between measures.

## **2.4 Procedure**

### ***2.4.1 Ethical approval***

Ethical approval was sought before commencing the study and was granted. A copy of the application and correspondence with the Chairperson of the Ethics Committee is included as Appendix 5.

### ***2.4.2 Pilot***

As the focus of the study was to investigate reliability and validity of the key measures, it was not considered necessary to conduct a detailed pilot study. The purpose of the pilot was both to allow the researcher to become familiar with the process of interviewing participants using the measures developed by Szivos-Bach (1993) and to finalise the items included in the measure of emotional well-being. Participants for the pilot study were recruited from a residential unit, and the process of establishing informed consent was followed as below (Section 2.4.5). The pilot study comprised administration of the social comparisons test, stigma questionnaire, aspirations-expectations test and the six-item measure of emotional well-being (Appendix 3).

### ***2.4.3 Discussion with day centre managers and staff***

The managers of two day centres for adults with learning disabilities were approached about the possibility of conducting the research in these settings. The managers then facilitated meetings in which the researcher presented her proposal to staff and discussed the implications of the research. A copy of the information sheet provided for staff is included as Appendix 6: this was also circulated to staff unable to attend the meetings. All staff agreed to the research proposal. Keyworkers were then asked to generate lists of clients who may be able to participate in interviews.

### ***2.4.4 Meetings with users***

A series of informal meetings were organised within each day centre with users who had been invited by their keyworkers and who wished to attend to find out more about the study. Approximately eight users attended each meeting, accompanied by a staff member to support clients and ensure their understanding of the information presented.

The researcher introduced herself as a student psychologist interested in finding out about "how people think about themselves and others, and how this affects their feelings". She explained that she would like to speak to as many people on their own as possible to ask some questions and talk to them about this. The days and location of the meetings (in the day centres) was made clear, as was the fact that meetings would be private and confidential (clients' understanding of this was checked). Clients were also invited to ask questions and express any concerns about the study. Meetings lasted about half an hour.

At the end of each meeting, interested clients were given letters about the study to take away and read (with keyworkers or parents as appropriate) in order to allow them time to think about the issues and decide whether or not to participate. The letters were worded with advice from the speech therapist and included a photograph of the researcher as a memory aid. A copy of the letter is included as Appendix 7.

Although consent to participate in the study was considered to be the clients' decision (as agreed by the centre staff and the Ethics Committee), information sheets about the study were also sent to parents/residential staff (Appendix 8). This ensured that clients who wished to discuss the study with people at home could do so with informed parties, and also provided a contact name and number for parents with queries or concerns. In fact this was only used by one parent.

#### ***2.4.5 Individual consent***

For clients who agreed to meet with the researcher on an individual basis, the purpose and process of the study was explained again to check their understanding of this. The researcher reminded participants that interviews were private, and that she would not discuss what the client said with anyone else unless he/she asked her to do so. The researcher also emphasised that if the client agreed to answer her questions, he/she could change their mind and stop the interview at any time. Only at this stage did she read through the consent form (Appendix 9) and ask participants to sign: these points were included on the form to ensure their comprehension. Photocopies of the consent forms were given to participants if required.

### **2.4.6 Individual interviews - data collection**

Interviews were scheduled to last between one and two hours, spread over two sessions if participants appeared fatigued. The interview schedule is included as Appendix 10 and is summarised below in Table 2.5.

**Table 2.5: Interview Schedule**

- 
- |    |   |
|----|---|
| a) | Introductory questions to check comprehension and orientation.<br>e.g. "What do you do here?", "Where do you live?". Participants to be excluded if they answer yes or no (after Szivos-Bach, 1993).  |
| b) | Background information (age, residential situation etc.).   |
| c) | British Picture Vocabulary Scale.   |
| d) | Questions to check ability to use five-point scale for social comparisons.<br>(after Helsel & Matson, 1988).<br>eg. Researcher demonstrates using the scale saying "Show me on the ladder how much you agree with these statements:"<br>I am good at making tea.<br>I can't get up in the mornings. |
| e) | Social Comparisons Test.  |
| f) | Stigma Questionnaire.   |
| g) | Questions to check ability to use three-point scale.<br>eg. "Tell me whether this is something you would like to do, not like to do, or you don't know: Go to the pictures this week".  |
| h) | Aspirations-Expectations test.  |
| i) | Zung Depression Scale (adapted).  |
| j) | Measure of emotional well-being.  |
- 

At the end of the interview, the researcher thanked participants and asked if they would agree to see her in a few weeks to answer some of the questions again.

### **2.4.7 Completion of Social Performance Survey Schedule**

After each individual interview, two copies of the SPSS were given to the manager/deputy manager for circulation to the staff most familiar with each



participant. Staff were instructed to complete the questionnaires independently and were asked to return them within two weeks.

#### **2.4.8 Retest interviews**

Participants were contacted again eight to twelve weeks after the initial interviews. For those agreeing to participate in the retest, the procedure for checking informed consent was repeated as above (Section 2.4.5) with completion of a second consent form.

Retest interviews were shorter, covering points (d) to (h) of the interview schedule (Table 2.5 above). The researcher commenced the retest session by asking participants whether anything had changed for them since the last meeting, or whether they were worried about anything at present.

### **Section 3: RESULTS**

Summarised results from the demographic data and individual measures are presented before consideration of the results in relation to the hypotheses of this study. Data were analysed using SPSS for Windows.

#### **3.1: Pilot**

Six people participated in the pilot study. As the pilot was intended to familiarise the researcher more thoroughly with the process of administration, participants' results will not be reported further here. The pilot served to highlight which items on the measure of emotional well-being were difficult for clients to comprehend: one item was omitted from the final version and additional wordings were created for others, as for the Zung depression scale (see Section 2.3.6).

#### **3.2: Participants**

Thirty-eight people were approached about the study, and 31 agreed to participate. The interview with one participant was terminated prematurely due to uncertainty about his comprehension of the measures. Thirty participants completed the initial interviews, a response rate of 79%.

Twenty-four people participated in the retest interviews. The retest interview was terminated prematurely with one participant due to evident fatigue, leaving a retest sample of 23 (76.67% of the original sample).

### **3.3: Length of interviews**

Initial interviews varied in length between one and three hours. Seven were spread over two sessions due to concentration difficulties and day centre timetables; one interview was spread over three sessions.

Retest interviews were shorter, between 45 minutes and 1 hour 45 minutes. Two were spread over two sessions.

### **3.4: Demographic Data**

Where t-tests are presented, Kolmogorov-Smirnov tests indicated no evidence that the data were not normally distributed.

#### **3.4.1 Gender**

Seventeen men and thirteen women took part.

#### **3.4.2 Age**

The mean age of participants was 37.37 years (SD=12.91, range 21-65 years).

T-tests for independent samples showed no significant difference in the distribution of ages between participants from each centre ( $M=34.13$ , 40.6 years), or

between males and females (37.71, 36.92 years respectively) (Tables A, B, Appendix 11).

3.4.3 Ethnicity

All participants were white UK/European.

3.4.4 Residential Situation

The majority of participants lived with their parents ( $N=19$ , 63.3%). Seven (23.3%) lived in staffed group homes, and four in other accommodation.

There were some differences between the centres, shown in Table 3.1, with more variety in types of accommodation among participants from centre 2.

Table 3.1: Number of participants in types of residential accommodation

	Parental home	GH <sup>a</sup> (staffed)	GH <sup>a</sup> (unstaffed)	Hostel	Other	Total
Centre 1	10	5	0	0	0	15
Centre 2	9	2	1	2	1	15

<sup>a</sup> group home

Due to small numbers in some categories, data were amalgamated into two groups: "living with parents" ( $N=19$ ) and "living elsewhere" ( $N=11$ ). T-tests for independent samples revealed no significant difference between groups according to IQ, but a highly significant difference was found for age ( $t=4.06$ ,  $d.f.=13.69$ ,  $p<.001$ ). Participants living with their parents were significantly younger than those living

elsewhere ( $M=30.95$ ,  $48.45$  respectively). Full results are presented in Table C in Appendix 11.

### **3.4.5 Work experience**

Ten participants were currently on some form of work experience, (five from each centre). Seven reported past experience of work placements (five from centre 1, two from centre 2), and 13 reported no work experience.

Participants were grouped into those who had present or previous work experience ( $N=17$ ) and those who had never worked ( $N=13$ ) in order to analyse differences according to gender (otherwise expected values would be too small in some cells). A Chi-Square analysis revealed no significant difference in work experience between men and women ( $\chi^2=1.47$ ,  $d.f.=1$ ,  $n.s.$ ). A t-test for independent samples revealed no difference between groups according to IQ, but a significant difference according to age ( $t= -2.23$ ,  $d.f.=28$ ,  $p<.05$ ). People with work experience were younger than those with no work experience ( $M=33.06$ ,  $43$  years respectively). The full set of results is presented in Table D, Appendix 11.

### **3.4.6 Physical disability**

Eight participants had a physical disability, 26.7% of the sample. Two were in wheelchairs; other disabilities included some degree of cerebral palsy, arthritis requiring use of a walking frame, and impaired vision.

Clients with disabilities were represented in both centres ( $N=3$ ,  $5$  respectively) and were both male and female ( $N=6$ ,  $2$  respectively). Their mean age was 44 years ( $SD=13.91$ , range 25-59 years). Mann-Whitney tests, used in

preference to t-tests due to the discrepant sample sizes ( $N=8, 22$  respectively), indicated no significant differences between the disabled and non-disabled participants according to age or IQ ( $Z= -1.39, -0.43$  respectively, n.s.).

### 3.4.7 BPVS (Dunn *et al.*, 1982)

Administration of the BPVS was discontinued with one participant due to impaired vision. Analyses are therefore based on the remaining 29 participants. Raw scores were converted into age equivalents (range 3 years,7 months-19 years for this sample).

Szivos-Bach (1993) reported IQ inferred from BPVS scores but did not report her method of calculation. For the purposes of this study, the equation used was

$$IQ = \frac{MA}{15} \times 100 \quad \text{where MA} = \text{mental age (age equivalent score)}$$

15

as described by Héaton-Ward and Wiley (1984).

The mean IQ obtained by this method was 57.86 ( $SD=23.11$ , range 23-127). This compares with a mean of 50.92 (range 19-92) reported by Szivos-Bach. Two participants obtained IQ equivalent scores over 100, which is high for someone receiving learning disability services. It should be noted that a measure of receptive language skills such as the BPVS can provide only an approximation to overall IQ.

IQ was not related to age (Pearson's product moment,  $r= -.12$ , n.s.; see Table 3.7) or gender (t-test for independent samples,  $t= -0.25$ , d.f.=27, n.s.; see Table B, Appendix 11).

### **3.5: Summary of Overall Questionnaire Responses**

#### **3.5.1 Social Comparisons Test (Szivos-Bach, 1993)**

Overall responses to the social comparisons test are summarised in Table 3.2.

The mean scores show a similar pattern of results to those obtained by Szivos-Bach (1993), with a mean Self score (93.22) higher than the mean score for Friend (87.78) but lower than Other or Ideal ( $M=102.97$ ,  $105.90$  respectively). High scores represent more positive ratings on this scale, with a maximum possible score for each comparison figure of 120. Mean scores for both Friend and Ideal are lower in this sample than those found by Szivos-Bach.

Table 3.2: Descriptive statistics for the social comparisons test

Comparison Figure		Mean score <sup>a</sup>	SD <sup>b</sup>	Range
Self <sup>c</sup>	- initial	93.22 (92.78)	12.32	59 - 114
	- retest	92.00	13.53	54 - 117
Friend <sup>c</sup>	- initial	87.78 (91.46)	15.78	50 - 107
	- retest	88.65	14.73	52 - 111
Other <sup>c</sup>	- initial	102.97 (98.74)	9.90	81 - 118
	- retest	98.96	15.74	44 - 115
Ideal <sup>c</sup>	- initial	105.90 (111.08)	10.42	73 - 119
	- retest	106.39	14.90	53 - 120

<sup>a</sup> Figures in parentheses from Szivos-Bach (1993)    <sup>b</sup> standard deviation

<sup>c</sup> comparison figures, social comparisons test  
N=30 at initial test, 23 at retest

No constraints were placed on participants in terms of their choice of friends or "other" comparison figures. The majority of participants chose friends at the day centres, with two choosing friends from group homes. Similarly, the majority of

participants ( $N=23$ ) chose day centre staff as the Other comparison figure: two chose group home staff and five chose another familiar person without learning disabilities.

Test-retest analysis is presented below (Section 3.6.1).

### 3.5.2 Stigma Questionnaire (Szivos-Bach, 1993)

High scores on this scale represent higher levels of experienced or perceived stigma. The current sample obtained a mean stigma score of 26.47 (possible range 10-50) and a similar retest score of 24.39. This is somewhat lower than the mean of 39.5 reported by Szivos-Bach (1993).

Overall responses are summarised in Table 3.3.

Table 3.3: Descriptive statistics for the stigma questionnaire

	Mean score <sup>a</sup>	SD <sup>b</sup>	Range
Initial test	26.47 (39.5)	7.38	13 - 38
Retest	24.39	6.99	12 - 33

<sup>a</sup>Figures in parentheses from Szivos-Bach (1993) <sup>b</sup>standard deviation  
 $N=30$  at initial test, 23 at retest

### 3.5.3 Aspirations - Expectations Test (Szivos-Bach, 1993)

The mean aspirations score (19.73) is similar to that obtained by Szivos-Bach (1993). She did not report data for the expectations score. Descriptive statistics for the aspirations-expectations difference are not similar, and eight participants (27%) in this study reported higher expectations than aspirations, a trend not found by Szivos-Bach.



Aggregated results are presented in Table 3.4.

Table 3.4 Descriptive statistics for the aspirations - expectations test

		Mean score <sup>a</sup>	SD <sup>b</sup>	Range <sup>a</sup>
Aspirations	- initial	19.73 (17.10)	4.07	11 - 24 <sup>c</sup>
	- retest	19.26	4.34	9 - 24
Expectations	- initial	19.10 <sup>c</sup>	3.65	12 - 24 <sup>c</sup>
	- retest	18.91	4.53	9 - 24
Difference (A-E)	- initial	0.63 (5.04)	3.29	-6 - 10 (0 - 11)
	- retest	0.43	3.12	-7 - 7

<sup>a</sup> Figures in parentheses from Szivos-Bach (1993) <sup>b</sup> standard deviation

<sup>c</sup> not reported by Szivos-Bach

N=30 at initial test, 23 at retest.

Closer analysis of the data showed that 30% of aspirations total scores (N=9) and 20% of expectations total scores (N=6) were 24, the maximum score possible. This is indicative of a ceiling effect for this measure.

#### **3.5.4 Zung Depression Scale (Zung, 1965)**

The mean score on the Zung Depression Scale was 40.23 (SD=7.93, range 23-59). This is comparable with results reported by Lindsay *et al.* (1994) (M=37.87, SD=10.04), and with the depressed sample in Kazdin *et al.* (1983), who reported means for their non-depressed and depressed sample of 30.9 and 38.3 respectively. The possible range of values on this measure is 20-80.

No relationship was found between Zung scores and age or IQ (Pearson's product moment, see Table 3.7) and there was no significant difference between males and females (t-test for independent samples,  $t = -0.78$ , d.f.=28, n.s., see Table B, Appendix 11).

### **3.5.5 Emotional well-being**

The mean score on this new questionnaire was 14.93 (SD=3.87, range 6-20). The range of scores indicates that participants were able to give a variety of responses using this scale, the possible range of scores being 5-20. Six participants (20%) scored 20, the maximum score possible, which may indicate a ceiling effect.

The scores for emotional well-being correlated negatively with the Zung depression scores (Kendall's Tau  $r = -.28$ ,  $p < .05$ : Table E, Appendix 11), indicating that participants reporting high levels of depression achieved low scores of emotional well-being and vice versa. This would be expected and provides preliminary evidence of construct validity for this measure.

Comparison of individual answers to the questions "I feel downhearted and blue" (Zung depression scale) and "I feel happy" (measure of emotional well-being) indicated that four participants (13%) gave incompatible responses, i.e. "quite a lot of the time" or "most of the time" to both statements.

Scores on the measure of well-being were not correlated significantly with age or IQ (Kendall's Tau, Table E, Appendix 11), or with gender (Mann-Whitney U,  $Z = -1.50$ , n.s.).

### **3.5.6 SPSS (Matson *et al.*, 1983)**

Fifty-six questionnaires were returned out of 60 (93.3% response rate), with complete data (two questionnaires, necessary for calculating inter-rater reliability) on 26 participants. Analyses reported below relate only to these 26.

The data were organised into two sets in order to test inter-rater reliability: SPSS1, the lower score achieved by each participant, and SPSS2, the higher

scoring questionnaire. The means for SPSS1 and SPSS2 were 121.56 (SD=32.32, range 66-165) and 137.79 (SD=34.53, range 68-177) respectively. The possible range of scores on the SPSS is 57-285.

A Kolmogorov-Smirnov Goodness of Fit test found no evidence that the difference between the two SPSS scores was not normally distributed. A subsequent t-test for paired samples indicated that SPSS1 and SPSS2 were highly correlated for individual participants ( $r=.94$ ,  $p<.001$ ), but that there was a highly significant difference between those scores ( $t= -6.78$ ,  $d.f.=25$ ,  $p<.001$ ). In other words, staff tended to rate individuals consistently in terms of awarding high or low scores, but pairs of scores differed by an average of 16 points. The implications are discussed further in Section 4 (Discussion).

For the purposes of further analysis, a single SPSS score was created for each participant by calculating the average of their SPSS1 and SPSS2 scores. The mean of the final SPSS score was 129.67 (SD=32.88, range 67.5-168). These figures were not reported by Matson *et al.* (1983), so it is not possible to make comparisons across studies.

No relationship was found between scores on the SPSS and age or IQ (Pearson product moment,  $r=.10$ ,  $.28$  respectively, *n.s.*, see Table 3.7) or with gender (t-test for independent samples,  $t= -0.14$ ,  $d.f.=24$ , *n.s.*, Table B, Appendix 11).

### **3.6: Analyses in Relation to Research Hypotheses**

Subsequent analyses are presented in relation to the original research questions.

#### **3.6.1**

***H1: The social comparisons test, stigma questionnaire and aspirations-expectations test are reliable measures over time.***

During the time-period between test and retest, the local authority announced plans for cut-backs in expenditure which would lead to considerable reductions in the provision of day services for people with learning disabilities. Participants were asked at the time of retesting whether anything important had happened - good or bad - since they last met the researcher, or if anything was worrying them at present. Seventeen out of out of 23 (74%) reported a negative concern, one reported a positive concern, and four reported no concern. One participant did not respond directly to this enquiry. The majority of those who reported a concern described their worries about the proposed cutbacks: some reported hearing that their centre was closing, or expressed how difficult it was when nobody really knew what was going to happen. These concerns were voiced in both day centres.

It was not possible to analyse whether retest scores differed for those expressing some or no concerns, due to the small numbers expressing no or positive concerns.

a) Social comparisons test.

Kolmogorov-Smirnov Goodness of Fit tests indicated no evidence that the differences between scores for each comparison figure in the social comparisons test were not normally distributed. The analysis of choice to explore the relationships between scores for four comparison figures (Self, Friend, Other and Ideal) at two points in time would therefore be a two-way analysis of variance. However, this was not possible due to the heterogeneity of the variances (Mauchley sphericity test,  $W=.32$ ,  $p<.001$ ). Instead, t-tests for repeated measures were employed for each comparison figure.

Table 3.5 shows that none of the comparisons were significant at the 5% level, indicating the results were reliable over time for this sample.

Table 3.5: T-tests for repeated measures on social comparisons data

Comparison figure	T (d.f.=22)
Self <sup>a</sup> - retest	-0.12
Friend <sup>a</sup> - retest	-1.17
Other <sup>a</sup> - retest	1.56
Ideal <sup>a</sup> - retest	-0.92

<sup>a</sup> comparison figures, social comparisons test  
N=23

b) Stigma questionnaire.

A Kolmogorov-Smirnov Goodness of Fit test indicated a normal distribution for the difference between individual scores for each presentation of the stigma questionnaire. A t-test for paired samples was therefore used to analyse test-retest reliability. The results were significant ( $t=2.29$ ,  $d.f.=22$ ,  $p<.05$ ). These results

indicate that scores on the stigma questionnaire were not reliable over time for this sample.

Possible reasons for the lack of test-retest reliability in this measure are explored further in the Discussion (Section 4).

c) Aspirations-expectations test.

Due to the smaller range of scores on this measure (11-24), results were analysed non-parametrically, using Kendall's Tau. Within-measure analyses were highly significant, shown in Table 3.6. All correlations were of the order of  $r=.5$ ,  $p<.01$ .

Table 3.6: Correlations for test-retest reliability of aspirations-expectations

	correlation coefficient ( <i>r</i> )
Aspirations - initial and retest	.49**
Expectations - initial and retest	.58***
Difference (A-E) <sup>a</sup> -initial and retest	.56***

\*\* $p<.01$ ; \*\*\* $p<.001$

<sup>a</sup> aspirations total minus expectations total

The correlations indicate that this measure showed good stability over time.

**3.6.2: Correlations for hypotheses 2 and 3.**

Table 3.7 details the overall set of correlations from which information for hypotheses two and three is taken. As Kolmogorov-Smirnov Goodness of Fit tests indicated no evidence that the scores were not normally distributed, Pearson's product moment was used to analyse correlations involving social comparisons and stigma data as the measures generate interval data with a large range of values.

Scatter plots (Appendix 12) indicated no non-linear relationships (this would have signified Spearman's correlation coefficient as the analysis of choice).

Table 3.7: Table of Pearson's correlations for social comparisons and stigma tests

Friend <sup>a</sup>	.44*							
Other <sup>a</sup>	.50**	-.06						
Ideal <sup>a</sup>	.82***	.29	.58***					
Stigma	-.48**	-.06	-.27	-.43*				
Zung <sup>b</sup>	-.58***	-.06	-.33	-.46**	.54**			
SPSS <sup>c</sup>	.11	.16	.23	.16	.09	.01		
IQ	.15	-.29	.19	.08	-.29	-.22	.28	
Age	-.10	-.01	.05	.06	-.47**	-.10	.10	-.12
	Self <sup>a</sup>	Friend <sup>a</sup>	Other <sup>a</sup>	Ideal <sup>a</sup>	Stigma	Zung <sup>b</sup>	SPSS <sup>c</sup>	IQ

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

<sup>a</sup> comparison figures, social comparisons test    <sup>b</sup> Zung depression scale

<sup>c</sup> Social Performance Survey Schedule

The analysis involves a large number of correlations and it is therefore possible that some significant results arise by chance. It is advisable in such instances to invoke the Bonnferroni criterion, which increases the rigour of the test, but this was not possible on the statistics package used.

### 3.6.3

***H2: High self-esteem as measured on the social comparisons test will correlate with low ratings of depression (Zung depression scale) and with good social and interpersonal skills (SPSS). Low self-***

***esteem will correlate with high depression scores and poor social and interpersonal skills.***

***Self-esteem will not correlate with gender, age or IQ.***

A significant negative correlation was found between scores on the Zung depression scale and self-esteem as measured by the Self score ( $r = -.58$ ,  $p < .001$ ). This was in the expected direction, i.e. high Self scores correlated with low depression scores and vice versa. No correlation was found with SPSS scores ( $r = .11$ , n.s., Table 3.7).

Self scores did not correlate with age or IQ ( $r = -.10$ ,  $.15$  respectively, n.s., Table 3.7). A t-test for independent samples revealed no difference between males and females on the Self score. ( $t = -0.48$ , d.f.=28, n.s., Table B, Appendix 11)

#### **3.6.4**

***H3: High scores on the stigma questionnaire will correlate significantly with high scores on the Zung depression scale and with low scores on the SPSS. Low perception of stigma will correlate with low depression scores and high scores on the SPSS.***

***Stigma scores will not be related to gender, IQ or age.***

A significant positive correlation was found between scores on the stigma and depression scales ( $r = .54$ ,  $p < .01$ ). This was in the expected direction, indicating that participants who reported experiencing higher levels of stigma tended to be more depressed than those who reported lower levels of stigma. No relationship was found between stigma and SPSS scores ( $r = .09$ , n.s., Table 3.7).



A highly significant negative correlation was found between stigma scores and age ( $r = -.47$ ,  $p < .01$ ), indicating that younger subjects tended to perceive more stigma than older subjects. This contradicted the third hypothesis. No relationship was found with IQ ( $r = -.29$ , n.s., Table 3.7) or gender (t-test for independent samples,  $t = -1.58$ , d.f.=28, n.s., Table B, Appendix 11).

These results must be interpreted with caution due to the lack of evidence for test-retest reliability for this measure (Section 3.6.1).

### 3.6.5

***H4: Small discrepancies between the aspirations and expectations scores will correlate significantly with low scores on the Zung depression scale and high scores on the SPSS. Large discrepancies will correlate with high depression scores and low SPSS scores.***

Due to the small range of recorded values for the difference between the aspirations and expectations scores, correlations were analysed non-parametrically, using Kendall's Tau (see Table E, Appendix 11 for full results). A significant negative correlation was found between the aspirations-expectations difference and the Zung score ( $r = -.34$ ,  $p < .05$ ), indicating that large positive discrepancies were correlated with low depression scores and vice versa, i.e. participants who reported higher aspirations than expectations also reported lower levels of depression. This is in the opposite direction from that predicted by hypothesis four. No relationship was found with the SPSS ( $r = .09$ , n.s.).

The aspirations-expectations discrepancy did not correlate with IQ or age ( $r=.16$ ,  $.05$  respectively, n.s.).

Correlations with the Zung and SPSS scores, and age and IQ, were also calculated for the total aspirations and expectations scores. Aspirations correlated strongly with expectations ( $r=.57$ ,  $p<.001$ ), and less strongly with the aspirations-expectations discrepancy ( $r=.37$ ,  $p<.01$ ) and with the SPSS score ( $r= -.30$ ,  $p<.05$ ). This indicates that subjects expressing high aspirations also tended to be rated as having poorer social skills, and vice versa.

Expectations correlated weakly with the stigma total ( $r=.29$ ,  $p<.05$ ), and negatively with the SPSS scale ( $r= -.36$ ,  $p<.05$ ) and age ( $r= -.28$ ,  $p<.05$ ). Due to the significant separate correlations between aspirations, expectations and SPSS scores, a partial correlation was calculated controlling for the expectations score. The relationship between aspirations and SPSS was then non-significant ( $r=.28$ , n.s.), indicating that the initial significant correlation was due to the strong correlation between aspirations and expectations.

### 3.6.6

***H5: Within the social comparisons test, subjects will rate themselves as similar to their friends. The Other and Ideal scores will be significantly higher than the Self score.***

Although the Kolmogorov-Smirnov Goodness of Fit test showed no evidence that the differences between paired scores for comparison figures were not normally distributed, an analysis of variance could not be used for the social comparisons

test due to the heterogeneity of the variances (see Section 3.6.1). Therefore, the relationships between comparison figures were analysed using t-tests for paired samples. The findings are summarised in Table 3.8.

Table 3.8: T-tests for paired samples, social comparisons test

Comparison Figures	Initial test T (d.f.=29)	Retest T (d.f.=22)
Self <sup>a</sup> - Friend <sup>a</sup>	1.96	1.29
Self <sup>a</sup> - Other <sup>a</sup>	-4.74***	-3.02**
Self <sup>a</sup> - Ideal <sup>a</sup>	-9.76***	-7.20***
Other <sup>a</sup> - Ideal <sup>a</sup>	-1.71	-4.32***

\*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> comparison figures, social comparisons test

The correlations between pairs of comparison figures in Table 3.8 were all at least  $r = .44$ , significant at the 5% level, indicating significant relationships between ratings for comparison figures for individual participants.

*Initial administration:* The Self score differed significantly from the Other and Ideal scores ( $t = -4.74, -9.76$  respectively,  $p < .001$  for both comparisons), Self scores being significantly lower than both Other and Ideal scores. A one-tailed t-test, appropriate because the hypothesis predicts the direction of difference between the mean scores, increases the significance value of the results still further.

The Self-Friend difference approached significance ( $t = 1.96, p = .06$ , 2-tailed test), with Friend scores tending to be lower than Self scores. This tendency was also reported by Szivos-Bach (1993).

Comparison of Other-Ideal scores on the initial administration revealed no significant difference ( $t = -1.71$ ,  $d.f. = 29$ ,  $n.s.$ ).

*Retest:* Similar results were obtained for the retest scores, with the exception of the Other-Ideal difference which was now highly significant ( $t = -4.32$ ,  $d.f. = 22$ ,  $p < .001$ ). In other words, participants on the retest rated the Other comparison figure significantly lower than their Ideal self.

### 3.6.7.

***H6: High self-esteem will correlate with low scores on the perception of stigma scale and with small discrepancies between the aspirations and expectations scores.***

There was a highly significant negative correlation between Self scores and stigma scores ( $r = -.48$ ,  $p < .01$ , Table 3.7), indicating that high self-esteem related to low perception of stigma and low self-esteem is related to high perception of stigma, as predicted. Due to the significant correlations between Self, stigma and the Zung score, a partial correlation was calculated controlling for the Zung score. The subsequent correlation between Self and stigma scores was non-significant, indicating that the original result was due to the strong relationship between each score and the depression ratings ( $r = -.20$ ,  $n.s.$ ).

No relationship was found between Self score and the size of discrepancy between subjects' aspirations and expectations, analysed non-parametrically using

Kendall's Tau ( $r=.05$ , n.s., Table E, Appendix 11). This does not support hypothesis six.

### 3.6.8.

***H7: High self-esteem will correlate with high scores on the measure of emotional well-being. Low scores of emotional well-being will correlate with high scores on the stigma questionnaire and large discrepancies between aspirations and expectations scores.***

Due to the small range of scores obtained on the emotional well-being measure (possible range 5-20), results were analysed non-parametrically, using Kendall's Tau (Table E, Appendix 11). This revealed a significant correlation between Self and well-being ( $r=.43$ ,  $p<.001$ ), in the predicted direction. No relationship was found with the perception of stigma scores ( $r= -.05$ , n.s.) or the aspirations-expectations difference ( $r=.05$ , n.s.), which does not support hypothesis seven.

## **3.7: Additional findings**

### **3.7.1 Analysis of responses according to demographic data**

#### *Residential situation*

Due to small numbers of participants in categories of residential situation other than parental home, data were analysed by amalgamating the other groups to create two categories: clients living with parents ( $N=19$ ) and clients living elsewhere ( $N=11$ ). T-tests for independent samples indicated no differences between these groups

according to levels of depression, SPSS ratings, self-esteem or stigma ratings. The full table of results is presented in Table C, Appendix 11.

Non-parametric tests were used to analyse scores on the well-being measure, due to the small range of values. Comparison of medians revealed no significant differences between groups (Mann-Whitney U,  $Z = -0.56$ , n.s.).

### *Work experience*

In order to assess the impact of work experience on other scores, participants were categorised into two groups; those who had current or previous work experience, and those with no work experience ( $N=17$ , 13 respectively). Kolmogorov-Smirnov Goodness of Fit tests found no evidence that the data were not normally distributed, and t-tests for independent samples found no differences between the groups on measures of depression, social comparisons, stigma or the SPSS. Full results are presented in Table D, Appendix 11. A non-parametric comparison of medians revealed a significant difference between groups on the measure of well-being (Mann-Whitney U,  $Z = -2.17$ ,  $p < .05$ ), with lower scores for those participants with no work experience.

### *Physical disability*

Due to an imbalance in the sample sizes for people with and without an additional physical disability ( $N=8$ , 22 respectively), it was not appropriate to carry out parametric statistical analyses. Nonparametric Mann-Whitney U tests found no differences between participants with and without a physical disability on all measures other than well-being: scores for those with a disability were significantly

lower than for the non-disabled group ( $Z = -2.29, p < .05$ ). This result should be interpreted with caution due to the small sample size and the non-standardised nature of the well-being measure.

**3.7.2 Social comparisons and gender**

As no constraints had been placed on participants in terms of gender for their choice of Friend and Other, the relationship between choice of gender and ratings of comparison figures was investigated further. T-tests for independent samples had revealed no significant difference between males and females in terms of overall scores for Friend and Other ( $t = -1.65, 0.35$  respectively,  $d.f. = 28$ , Table B, Appendix 11).

The data were then categorised according to whether participants chose comparison figures of the same or a different sex. The total number choosing a Friends or Other of the same gender was 18 and 12 respectively; those choosing a different-sex Friend or Other numbered 12 and 18 respectively. Figures according to the gender of participants are presented in Table 3.9.

Table 3.9: Numbers choosing comparison figures of same/different sex

Self	Friend		Other	
	Male	Female	Male	Female
Male	11	6	6	11
Female	6	7	7	6

Kolmogorov-Smirnov Goodness of Fit tests indicated no evidence that the differences between Self and Friend/Other scores for people choosing comparison figures of the same versus different sex were not normally distributed. The variances

of these differences differed by a factor of more than 3, indicating that it was not possible to analyse the groups using an analysis of variance (Griffiths, personal communication). Instead, t-tests for paired samples were conducted for Self-Friend (same versus different-gender) and Self-Other (same versus different-gender). Results of the t-test are summarised in Table 3.10 and are explained in more detail below.

*Self-Friend comparison:* The mean scores for Self and Friend of a different sex were significantly correlated ( $r=.73$ ,  $p<.01$ ) and did not differ significantly ( $t= -0.38$ ,  $d.f.=11$ , n.s.). The means for Self and Friend of the same sex did not correlate and a significant difference was found ( $t=2.48$ ,  $d.f.=17$ ,  $p<.05$ ). This indicates a tendency for people to rate friends of the same sex more negatively on comparison measures than themselves or friends of the opposite sex. Numbers were too small to compare males and females in this respect.

Table 3.10: Paired samples T-test for analysis of self-friend/other scores according to choice of comparison figures of same or different gender.

	N	Mean scores	SD	r	T	d.f.
Self <sup>a</sup>	18	94.53	11.13	.37	2.48*	17
Friend <sup>a</sup> (same) <sup>b</sup>		84.75	17.36			
Self <sup>a</sup>	12	91.25	14.21	.73**	-0.38	11
Friend <sup>a</sup> (diff) <sup>c</sup>		92.33	12.36			
Self <sup>a</sup>	12	91.08	14.53	.43	-2.02	11
Other <sup>a</sup> (same) <sup>b</sup>		98.92	9.07			
Self <sup>a</sup>	18	94.64	10.82	.55*	-4.77***	17
Other <sup>a</sup> (diff) <sup>c</sup>		105.67	9.73			

\*  $p<.05$ ; \*\*  $p<.01$ ; \*\*\* $p<.001$

<sup>a</sup> comparison figures, social comparisons test    <sup>b</sup> same gender as Self

<sup>c</sup> different gender from Self



*Self-Other comparison:* Mean scores for Self and Other of the same sex were not correlated ( $r=.43$ , n.s.), and were not significantly different ( $t= -2.02$ , d.f.=11, n.s.).

The mean scores for Self and Other of the opposite sex correlated significantly ( $r=.55$ ,  $p<.05$ ), and a highly significant difference was found ( $t = -4.77$ , d.f.=17,  $p<.001$ ).

This analysis implies that the participants rated other people without learning disabilities more highly if they were of the opposite sex to themselves. Therefore, for both Friend and Other, participants rated them more positively if they were of the opposite sex.

### **3.7.3 Value of components of social comparisons test**

In order to assess the usefulness of the social comparisons test further, a stepwise multiple regression was performed to identify the most important questions and their contribution to the total Self score. The analysis revealed that 8 questions explained 96% of the variability of the total score (Multiple  $R=0.98$ ,  $R\text{ square}=0.96$ ;  $F=55.91$ , d.f.=8, 21,  $p<.0001$ ). This is a large number of predictors given the sample size in this study, but the results are highly significant, and the contribution of each chosen question itself is significant, as shown in Table 3.11.

In terms of Coopersmith's (1967) dimensions of self-esteem, questions 3, 4, 5 are from the Power/Significance dimension, 15 from Virtue/Values and 19, 20, 22, 23 from Competence. Virtue/Values is under-represented in this analysis and question 15 contributes least to the significance of these values. This may indicate that this dimension is not as salient to people with learning disabilities as to

Coopersmith's subjects, or that the items chosen by Szivos-Bach do not effectively elicit this dimension. The implications are discussed further in Section 4.

Table 3.11: Results of multiple regression of social comparisons

Question	B	T
3. I am good at making friends	3.90	5.89****
4. I get on with the opposite sex.	2.50	5.00****
5. I am lonely.	1.71	3.49**
15. I tell lies.	1.53	2.46*
19. I give up easily.	1.41	2.85**
20. I am slow at work.	1.97	4.01***
22. I can speak well in front of others.	5.58	7.60****
23. I make a mess of things I try.	1.75	3.29**
(Constant)	13.17	2.86**

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$ ; \*\*\*\*  $p < .0001$

### 3.8: Summary

Thirty people with mild or moderate learning disabilities took part in the study. They formed comparable samples of men and women of a wide age range.

The results found equivocal evidence in support of the hypotheses of reliability and validity of the measures of social comparisons, stigma and aspirations-expectations devised by Szivos-Bach (1993). Some evidence for the reliability and construct validity of the social comparisons measure has been established for this sample. Test-retest reliability of the stigma questionnaire was not found, though some significant results were supportive of its construct validity.

The aspirations-expectations measure was reliable over time, but little evidence of construct validity was established and there appeared to be a ceiling effect for this measure.

Closer analysis of the pattern of results within the social comparisons test revealed some evidence of downward comparisons towards others with learning disabilities and upwards towards non-learning-disabled people. A consistent gender effect was evident in terms of participants rating comparison figures of the opposite gender more positively than same-gender comparison figures.

There is an indication that older clients report experiencing higher levels of stigma, though the reliability of this measure has not been demonstrated. Older participants were also less likely to live with their parents or to have current or prior work experience.

The implications of these results are considered in depth in Section 4.

## **Section 4: DISCUSSION**

### **4.1: Summary of research findings**

The study aimed to establish the reliability and validity of Szivos-Bach's (1993) measures of self-esteem, stigma and aspirations-expectations. For each aspect of this analysis, some significant and non-significant results were found.

#### ***4.1.1 Reliability***

Both the social comparisons and the aspirations-expectations tests were reliable over time for this sample. Scores on the stigma questionnaire were not found to be reliable.

#### ***4.1.2 Validity***

The measures chosen to assess construct validity were the Zung depression scale (Zung, 1965), the Social Performance Survey Schedule (Matson *et al.*, 1983) and a new measure of emotional well-being.

Significant correlations with the Zung scale were found, such that low levels of depression correlated with high self-esteem (the Self score from the social comparisons test) and high levels of depression with high levels of reported stigma. The Zung depression scale also correlated with the aspirations-expectations discrepancy, but in the opposite direction to that predicted, so that participants

reporting lower expectations than aspirations also reported lower levels of depression.

Ratings on the SPSS did not correlate with self-esteem or reported stigma for this sample. A negative correlation with the aspirations and expectations totals was explained by the high association between the latter variables.

The measure of emotional well-being correlated significantly with self-esteem but not with stigma or aspirations-expectations scores. Participants with high self-esteem reported more positive states of well-being.

#### ***4.1.3 Additional findings***

Within Szivos-Bach's (1993) measures, the correlation between the Self score and the stigma score was explained by their independent associations with the Zung depression scale. Neither scale correlated with the aspirations-expectations scale, other than a correlation between perceived stigma and expectations, significant at the 5% level. This may be an artefact of the high number of correlations carried out, and again is not in the predicted direction.

An interesting effect of gender was found for the social comparisons test, in that participants rated both friends and others more negatively if they were of the same sex as themselves. Comparison figures without learning disabilities and of the same gender as participants were not rated as significantly different from the Self.

An effect of age on the stigma score was also found, in that older participants reported experiencing more stigma than younger participants. Younger participants

were also more likely to live with their parents and to have had some work experience.

Further analysis of the social comparisons test by a stepwise multiple regression revealed that eight questions accounted for 96% of the variability of the total score (Section 3.7.3). Seven questions represented the dimensions Power/Significance and Competence (Coopersmith, 1967); the third dimension on which the questionnaire is based, Virtue/Values, was under-represented in this analysis.

There was some initial evidence for the validity of the measure of emotional well-being, in that scores correlated negatively with levels of depression and positively with self-esteem. This suggests that there is scope for developing a more extensive and multi-dimensional measure of emotional well-being. The finding that people with physical disabilities gave lower ratings of well-being than others also warrants further investigation with larger numbers to establish whether this is a reliable effect. The measure of well-being will not be considered further in detail as discussion of its validity is not central to the thesis of the research.

#### **4.2: Methodological considerations**

A number of methodological criticisms must be acknowledged which may weaken the findings of this study.

#### **4.2.1 Sample size:**

The study aimed to recruit between 30 and 50 participants. Due to the lengthy interviews required for data collection and time restraints, it was only possible to reach the minimum sample proposed. While this represents a sufficient number for statistical analysis, results would be stronger if based on a larger sample. It would also then be possible to analyse differences between subgroups in more detail, such as exploring the effect of participants' gender on ratings for Friend and Other of the same or opposite sex.

#### **4.2.2 Method of recruitment**

It is possible that the sample was not truly representative of people with mild or moderate learning disabilities between the ages of 18 and 65, due to the recruitment method, i.e. reliance on staff recommendation. While the researcher had explained the need to target as broad a sample as possible, staff were required to make some judgement about the ability of clients to participate, and their willingness to do so.

The sample cannot be assumed to be representative of people with learning disabilities who are not in receipt of local authority day service provision: the results of this study may be influenced by factors specific to this environment.

#### **4.2.3 Inter-rater reliability**

An attempt was made to assess the inter-rater reliability of the Social Performance Survey Schedule (Matson *et al.*, 1983), using ratings from two independent sources. Although the paired ratings correlated, they were also significantly different, raising

doubts about the usefulness of this measure. There are a number of possible explanations for this finding:

a) The instrument itself is not valid and reliable. Evidence in the literature is not as comprehensive as one would hope (see Section 2.3.7, Method). This study found considerable variety in ratings by different individuals.

b) The measures of self-esteem and stigma are themselves invalid and unreliable. The stigma questionnaire was not found to be reliable over time, which may weaken the likelihood that it will have construct validity with the SPSS.

c) Interpersonal and social skills are not related to self-esteem or perception of stigma, so that the SPSS is not a useful measure of construct validity. It was hypothesised that people with less appropriate interpersonal skills would also have lower self-esteem (the causal direction of this relationship was not debated). This may be complicated by a lack of insight on the part of people with less appropriate social skills: insensitivity to social cues about inappropriate behaviour may also protect them from assaults on their self-esteem. One way of establishing whether this is the case for at least a subgroup of clients may be to complete both other- and self-report versions of the SPSS. Significantly higher scores on the self-report version *may* be indicative of a lack of insight.

d) Staff are not sufficiently aware of clients' abilities in social situations to make reliable judgements. Rather than being a specific criticism of staff in direct care settings, some discrepancy between self and other ratings can



be expected in any research comparing the two. Recognition of the difficulties inherent in adopting this approach was outlined in the Method (Section 2.3.7).

All other data were collected by the main researcher in individual interviews. While the interview schedule and method of administration was therefore consistent, inter-rater checks on the recorded data could not be made. This may reduce the potential for cross-study comparisons: certainly it is possible that differences between the results of this study and Szivos-Bach (1993) could be accounted for by “examiner effects”.

The need to establish inter-rater reliability for this measure must be addressed if it is to be standardised further, but the method used may require more resources (in terms of researchers at least!) than was possible in this instance. One possibility here was to tape-record a proportion of the interviews for assessment by a second researcher. It was felt this may be perceived as confusing and intrusive by participants who were being told that the researcher would not discuss their conversation with anyone else.

#### **4.2.4 Measures**

As the set of measures developed by Szivos-Bach (1993) is effectively three separate tests measuring different aspects of self-perception, it may have been more appropriate to use different comparison measures to assess the construct validity of each. An initial indicator of this is the finding that the comparison

measures (the Zung depression scale, SPSS and the measure of emotional well-being) did not correlate with the target measures in a consistent way.

A related methodological concern is the lack of standardised measures available for use in research of this kind. Difficulties with the SPSS have already been discussed. Particular concern was also raised about the usefulness of the BPVS as an indicator of IQ. Though it has frequently been used in this way, this has been described as a “misuse” of a measure for a specific ability (receptive language skills) as an estimate of global ability (Burland & Carroll, 1971). Hobson and Lee (1989) proposed that the BPVS is partly a test of emotional understanding, based on their observation of specific difficulties on emotion-related pictures for people with autism. They argued that subjects may attain misleadingly high scores on single-word vocabulary tests, which would fit the pattern of results in this study. In this case, it is not possible to conclude on the basis of these results that IQ does not correlate with self-esteem.

#### ***4.2.5 Length of interviews***

Administration of the measures was lengthy for some participants. While only one interview (retest) was discontinued due to fatigue, initial interviews were postponed with a number of participants who appeared tired or lacked concentration. The researcher's impression is that participants experienced little difficulty in returning to the tests at a later date and their responses remained consistent, but it may be important to assess the robustness of this approach in a more objective manner.

### **4.3: Interpretation of results**

As the study investigated a set of three measures, interpretation of results relating to each is considered in turn.

#### ***4.3.1 Social comparisons test***

Some evidence was found for the reliability and validity of the social comparisons test in this sample, in terms of stable responses across time, a negative correlation with levels of reported depression, and a positive correlation with emotional well-being. The pattern of ratings for comparison figures in relation to the self was similar to Szivos-Bach (1993), in terms of a (non-significant) tendency to downward comparisons towards friends with learning disabilities and significantly positive ratings of others without learning disabilities compared to self. On the initial administration, ratings of comparison figures without learning disabilities did not differ significantly from participants' ideal comparison figures.

An alternative explanation for this pattern of ratings is to consider the role of "examiner effects". Participants are in effect asked to give their judgements on a "person without a learning disability" to another "person without a learning disability". These people also share a professional identity as "service providers". The high ratings offered for most comparison figures who were not learning disabled could therefore be a product of the test situation rather than reflecting clients' true perceptions.

It would be difficult to redesign the measure to control for this effect. Administration of the questions is reliant on an "administrator" who by definition does not have learning disabilities. The significant difference between Ideal and

Other scores in the retest could reflect a reduction in the “examiner effect” due to familiarity: however, the shift can also be explained by consideration of the environmental changes and uncertain atmosphere throughout day service provision during the retests. Further research would be necessary to establish whether this reduction is commonly seen over repeated administrations of the measure.

If the social comparisons measure is reliable and consistently correlated with depression scores, the question remains as to precisely what is being measured. It was designed as a measure of self-esteem (Szivos-Bach, 1993) and is therefore based on Coopersmith’s (1967) dimensions of self-esteem. The multiple regression, however, revealed that the questions relating to one of these dimensions, Virtue/Values, had little predictive value in determining the total Self score. The analysis implies that the important factors are (i) roles within the social sphere (“I am good at making friends”; “I get on with the opposite sex”; “I am lonely”, from Power/Significance) and (ii) competence in demand situations (“I give up easily”; “I am slow at work”; “I can speak well in front of others”; “I make a mess of things I try”, from Competence). Less weight was placed on questions relating to social norms, the only significant predictor being “I tell lies”.

How does this relate to the definition of self-esteem? Self-esteem was defined as “the evaluative aspect of one’s self-concept in relation to others” (Introduction, Section 1.1), and the social comparisons test assesses self-ratings in comparison to others indirectly (participants were not asked directly if they thought they were better or worse than their comparison figures). Robson’s (1989) definition of self-esteem refers to “a person’s appraisal of his own worth, significance,

attractiveness, competence and ability to satisfy his aspirations". This can be related approximately to Coopersmith's dimensions as follows:

Power/Significance	- "significance" and "attractiveness" (social)
Competence	- "competence" and "ability to satisfy his aspirations"
Virtue/Values	- "worth"

There are similarities between items on Szivos-Bach's social comparisons measure and Robson's measure of self-esteem, e.g.:

<u>Szivos-Bach (1993)</u>	<u>Robson (1989)</u>
I get picked on	I often feel humiliated
I give up easily	If a task is difficult, that just makes me all the more determined
I look nice	I look awful these days
I am helpful to others	I have a pleasant personality

Similar comparisons could be made with questionnaires such as the Rosenberg self-esteem inventory (1965) and the Piers-Harris self-concept scale (1964) and are indicative of face validity of the social comparisons test as a measure of self-esteem.

The results of the multiple regression, however, indicate that many items contribute little to the overall self-esteem rating. If this pattern of results is repeated with other samples, it may follow that the salient factors in self-esteem for people with learning disabilities differ qualitatively from non-learning-disabled people. It would then be more meaningful to reconstruct the questionnaire incorporating the

most salient items and introducing new items which are expected to elicit specific constructs related to self-esteem for people with learning disabilities. These may include specific questions about feeling different and stigmatisation.

#### **4.3.2 Stigma questionnaire**

The study found limited evidence of construct validity for this measure and a lack of test-retest reliability. It is possible that the retest scores were particularly affected by the uncertainty surrounding day service provision at this time. Comparison of scores at test and retest did not show a significant increase in ratings of stigma on retest, but there was a lack of consistency across time for individuals. Anecdotal evidence from conversations with clients at the day centres indicated that they were affected in different ways by the changes; the majority were upset and angry at the prospect of losing services, but some responded by becoming politically active, engaging in client and public meetings and in at least one case speaking to the press; others waited passively for developments and talked about their parents' campaigning roles. Thus, the potential impact on ratings of stigma could be positive, perhaps by a process of consciousness-raising, "developing a strong and positive group identity by acknowledging and 'owning' the stigma" (Szivos & Griffiths, 1990), or negative, via mechanisms of victimisation and learned helplessness (c.f. Abramson *et al.*, 1978).

A negative correlation was established between stigma and age. This must be interpreted with caution due to the inconclusive evidence for reliability and validity and the large number of correlations employed, but it may indicate an avenue for further research. The younger participants, who reported experiencing

lower levels of stigma, were also more likely to live with their parents and to have current or previous work experience. This effect would have been masked in Szivos-Bach's (1993) sample because participants were all young adults.

If age is found consistently to correlate negatively with stigma scores, this may be interpreted in a number of ways:

- a) People with learning disabilities experience (or perceive) increased levels of stigmatisation as they grow older.
- b) Younger people with learning disabilities experience less stigmatisation due to protection by parents or easier access to supportive environments such as supervised work placements: older people in similar situations would also give lower ratings of stigma, but are less likely to be in such protective environments.
- c) The significant difference is due to a cohort effect: older people with learning disabilities have had different life experiences from the younger group. They have experienced the effects of more recent changes in service philosophy such as normalisation (Wolfensberger, 1972) only in their adult life, and may also have had quite different experiences of schooling. Formalised education for people with learning disabilities has only been mandatory over the past 15 years (Education Act, 1981; Gulliford, 1985). In the USA, Ingalls (1978) reported that just 8% of people with moderate learning disabilities were enrolled in schools in 1953. Thus the pattern of discrepancies in stigma scores for younger and older participants may change across generations.

### 4.3.3 Aspirations-Expectations test

The aspirations-expectations test was reliable over time in this study, but no evidence was found for construct validity. This may be due to an inappropriate choice of measures, though the correlation with levels of depression was actually in the opposite direction from that predicted: participants with higher aspirations than expectations reported less symptoms of depression rather than more. Doubts about the usefulness of this measure are increased by the evidence of a ceiling effect on ratings of both aspirations and expectations, and by the high proportion of participants (27%) who reported higher expectations than aspirations.

The reason for this pattern of responses, and the discrepancy with Szivos-Bach's findings, is unclear. Anecdotally, one participant reported aspiring to few of the items on the test because "my mum says I don't want to do that", and it is possible that such messages also influenced other responses. These participants may therefore have given what they perceived to be the *right*, expected response. It is not possible to judge the honesty of participants' reports of high expectations. It may have been too painful to admit to a relative stranger that they did not feel able to achieve such common goals: alternatively, the clients expressing high expectations may also lack insight into the limits of their abilities.

Of course, not all the items represent impossible goals. Many participants replied to question two with "Yes, I've already got one [a boyfriend/girlfriend]". A minority of people with learning disabilities do marry and have children, and the researcher also knows of one client who drives a moped to his day centre (Curley, personal communication).



#### **4.4: Relation to previous research**

##### ***4.4.1 Development of a measure of self-esteem***

A major criticism of previous research was the wide range of approaches to the measurement of self-esteem. This study has begun the process of standardisation of a measure designed specifically for use with people with learning disabilities, and parallels the process of development in other fields (Robson, 1989).

Although direct comparisons of the findings can only be made with Szivos-Bach (1993), due to the variety of approaches to self-esteem measurement, a number of similar patterns emerge across the literature.

##### ***4.4.2 Social comparisons - with friends***

The tendency for "downward comparison" towards other people with learning disabilities reported by Szivos-Bach (1993) was replicated in this study on both initial administration and retest, though the findings were not statistically significant. This pattern is also comparable with Gibbons (1985), who found that participants rated people in photographs more negatively if told they were "retarded". Oliver (1985) reported that his subject rated herself on a repertory grid as more like her ideal than her friend with learning disabilities, though care must be taken in making generalisations from a single case-study.

A factor which has not been addressed directly in the literature is the effect of gender on social comparisons. In this study, the tendency to downward comparison of friends disappeared for participants rating friends of the *opposite* sex, but became

statistically significant for ratings of same-sex friends. Szivos-Bach did not report a similar analysis. Gibbons (1985) only used opposite-sex pairs; while he did find a downward comparison effect, he was asking subjects to rate strangers rather than friends.

Before assuming that the results of this study are robust, it is necessary to repeat the analysis with further samples. It would also be important to ask participants to rate friends of both genders in order to assess whether this pattern is due to some characteristic of the people who are more likely to *choose* opposite-gender comparison figures, rather than being a general tendency. Szivos-Bach (1993) did report some analyses regarding gender with reference to ratings of siblings, and interestingly found an opposite effect; participants rated themselves as superior to their opposite-sex siblings and inferior to their same-sex siblings.

A literature search of articles relating to social comparisons theory has not indicated comparable data for same-gender versus different-gender comparisons among people without learning disabilities. Attention has focussed on primary gender effects (see Schwalbe & Staples, 1991).

#### **4.4.3 Social comparisons - with others**

Initial analyses of ratings of non-learning disabled comparison figures in this study indicated that participants saw them as different (statistically) and more capable than themselves, which replicated Szivos-Bach's findings. The effect was again found to be related to gender, in that comparison figures of the same sex were not rated as significantly different from the self; opposite-sex comparison figures were still seen in a more positive light. This has not been reported in the literature

reviewed here: Jahoda *et al.* (1988) found that nine of their sample of 12 saw themselves as “essentially the same” as non-disabled people, but comparisons according to gender were not reported.

#### **4.4.4 Relationship between self-esteem and depression**

The significant negative correlation found between ratings of self-esteem and depression compares well with previous research with both learning disabled and other populations. Benson & Ivins (1992) reported a relationship between high levels of depression and low self-esteem using a measure adapted from work with children. Robson (1989) also employed a measure of depression (the Beck Depression Inventory; Beck, 1961) as a check of construct validity for his self-esteem questionnaire and found a significant negative correlation.

Correlational evidence as such cannot prove a causal connection, as discussed in the Introduction (Section 1.2). Thus, low self-esteem may lead to depressive episodes, act as a vulnerability or mediating factor, be a consequence of depression or be linked indirectly through some central factor. The consistent pattern of results across different methodologies and populations does, however, indicate the robustness of the relationship.

#### **4.4.5 Experience of stigmatisation**

Research into the experience of stigma has often been based on qualitative or observational methods (Edgerton, 1967; Gilkey & Zetlin, 1987; Griffiths & Szivos, 1990). Szivos-Bach (1993) proposed that her stigma questionnaire may be “a useful tool in further research”: this study throws doubt on its reliability. It may be that

acknowledgement of painful experiences of feeling different is only possible with the use of facilitative, unstructured interviews or group settings in which participants share common experiences (Griffiths & Szivos, 1990). Items on a brief objective measure such as the stigma questionnaire may not relate directly to personal experience.

Alternatively, experiences of stigma may be most pertinent and painful at the adolescent/young adult stage, as for the sample in Szivos-Bach's study. The people involved in this study were considerably older and comparisons with non-disabled peers may lose significance with age. (This would be counter to the trend observed in this study, but doubt has been cast on the reliability of these results.) A life-cycle perspective emphasises the importance of the stage of adolescence in identity-formation (Garcia-Preto, 1989); this task may be particularly difficult for people with learning disabilities to negotiate (Baker, 1991).

Another avenue for interpretation is to consider the impact of changing social policy on the self-concept of people with learning disabilities. As a relatively disempowered group, reliant to a large extent on the current social climate for their quality of life, it may be expected that experiences of stigma in terms of degree and type will vary for cohorts of clients of different generations and locations. A modern study adopting the methodology of Edgerton (1967) may therefore find less evidence of "passing" as a coping mechanism, and observe an increased emphasis on "consciousness-raising" and attempts to establish a positive in-group identity (Szivos & Travers, 1988; Szivos & Griffiths, 1990).

In terms of understanding the factors which contribute to the experience or perception of stigma, it is important to listen to the clients' perspective rather than

impose a framework designed solely from the researcher's expectations (c.f. feminist models of research, Walmsley, 1991). Although the stigma items developed by Szivos-Bach were based loosely on two previous studies, the studies had not specifically elicited the views of adults with learning disabilities. It may be that people such as the participants in this study are affected in only a minor way by, e.g., verbal abuse from strangers, and their self-esteem is dependent instead on factors such as the stability of personal relationships. These ideas cannot be explored further in the context of limited findings from this study, but warrant further research.

#### ***4.4.6 Methodology for research with people with learning disabilities***

The brief review of research methods in the Introduction (Section 1.5) indicated the importance of enabling clients to explain their responses, in terms of using open-ended questions or semi-structured interviews. While the data collected in this study were quantitative, the method used involved talking with clients about each response in order to ensure the validity of their responses. In addition, visual scales and verbal labels were employed to make the task more concrete; none of the clients experienced difficulty in relating the social comparisons items to a ladder and person-shaped counters. Use of verbal labels for each rung of the ladder may correspond to creating multiple-choice questions, which would also fit the recommendations of Chapman & Oakes (1995) and Zetlin *et al.* (1985).

Visual prompts for the measures of stigma, depression and well-being were four and five-item bar charts, an approach which had been used with success in previous studies (e.g. Kazdin *et al.*, 1983). It may be that participants found the

switch from the ladder to a new rating scale confusing, which could have influenced the variability of stigma ratings.

The aspect of methodology which was most helpful from the researcher's subjective viewpoint was the development of relationships with most participants outside the interview situation. As the researcher became a regular visitor to both centres over several months, it was inevitable that she was recognised and welcomed, and people showed considerable interest in her work. The benefits of this arrangement were perhaps increased trust in the confidential nature of the interviews (which may contribute to reduced ratings of Other comparison figures in the retest), a good response rate in terms of participants, and little evidence of "acquiescence" (Shaw & Budd, 1982). For example, a number of clients were able to tell the researcher in person that they did not want to participate in the research. Simons *et al.* (1989) advocated the importance of an extended familiarisation period when planning research with people with learning disabilities, and it is thought that the careful preparation for this study went some way to achieving this.

In line with the principles of feminist research outlined by Walmsley (1991), it is also intended to feedback the results of this research to the participants and staff at the day centres to allow people to see the outcome of their involvement in the study and to facilitate joint discussion of the implications.

#### **4.5: Clinical implications**

The clinical implications of an initial study to assess the reliability and validity of a self-esteem questionnaire can only be tentative. Arguments for promoting the

development of standardised measures for this population were outlined in the Introduction. It is expected that a valid self-esteem measure such as the social comparisons test will prove beneficial in clinical settings at least with verbally able people with mild or moderate learning disabilities, particularly in providing an objective measure to complement the initial assessment process and to monitor progress over time. A link with levels of depression has been demonstrated in this study: further research may indicate other mental health difficulties which impact on (or are affected by) low self-esteem in this client group.

In addition to monitoring individual progress, the measure could prove useful in assessing the efficacy of groupwork. Indeed, more significant improvements in self-esteem may be found with groupwork due to opportunities for social support and shared experiences, as reported by Griffiths & Szivos (1990).

On a qualitative note, experience from conducting the research indicates that the social comparisons test may prove a useful tool in the engagement process. The large majority of participants reported enjoying completing the measure, and expressed some regret when the retest interviews were over. The measure was easily understood and did not appear to be perceived as threatening or intrusive. There is also little indication to clients of what might be "the right answers", a factor which probably contributed to its reliability and validity in this study.

Robson's (1989) criteria for a clinically useful measure are that it should be easily comprehensible to clients, quick to complete, and "demonstrating satisfactory psychometric properties without sacrificing intuitive breadth of meaning". How does Szivos-Bach's social comparisons test compare? It seemed to be quite easily understood by this client group. It was not quick to complete, though it could be

argued that speed of completion entails sacrificing a certain amount of reliability for people with learning disabilities. Initial research into its psychometric properties is promising, though the same recommendations cannot be made about the measures of stigma and aspirations-expectations.

Robson (1989) also outlined the need to develop multi-dimensional measures of self-esteem, to enable exploration of the relative importance of different factors. An attempt to consider this has been made in terms of analysing which individual items are predictive of the total self-esteem score. Due to the highly significant results, it may be appropriate to refine the measure by omitting non-significant items and creating other more relevant items, perhaps specifically addressing ideas of stigma. The non-threatening nature of the social comparisons format has been noted, and participants may give more meaningful responses to items about "difference" using this format.

#### **4.6: Research implications**

Reference has been made to implications for further research at various points in this discourse. A number of disparate avenues could be pursued: a few are highlighted here.

- a) Further investigation of the validity and reliability of the social comparisons measure. One approach would be assessment of concurrent validity by comparison with an existing self-esteem questionnaire, such as the McDaniels-Piers Young Children's Self-Concept Scale (McDaniels & Piers, 1973). If it is to be adopted as a self-esteem questionnaire, it is



important to build up a database of patterns of responses across age-groups and settings to calculate norms. The instrument then has a much-needed role in research and clinical applications.

b) Associated with (a) is the need to establish the contribution of items within the social comparisons test, perhaps by replicating this study to compare results of a stepwise multiple regression, and to adapt the scale if necessary. On a purely subjective note, the item "I do as I am told" seems unnecessarily loaded for use with an historically disempowered client group; is it positive for an adult to give an affirmative response to this item? It may be productive to introduce new items and assess versions of the test with large samples.

c) Replication of the study with reference to the measures of stigma and aspirations-expectations will help to determine whether the failure to replicate Szivos-Bach's findings was an artefact of some aspect of this study.

d) Further investigation of gender-effects on social comparison ratings with larger samples. This has implications for the general understanding of the experiences and perceptions of this client group, and comparison with social processes in the general population.

e) Investigation of the impact of social policy and service developments on clients themselves. The lack of attention to self-esteem as an aspect of quality of life was noted in the Introduction (Section 1.6): a recent article by Felce (1996) offering a "framework for thinking about outcome" in terms of monitoring services at last incorporates a section on

“emotional well-being”. One factor specified within this is self-esteem, with the recommendation that “more needs to be done to develop measures of emotional well-being and affective state”. Clearly the social comparisons measure has the potential to contribute to this neglected area.

f) Research into self-esteem with people with severe and profound learning disabilities. This cannot be pursued here, but these measures are unlikely to be applicable and other methods of assessing well-being and esteem need to be developed.

#### **4.7: Conclusion**

This research represents the first steps towards the development of a valid and reliable measure of self-esteem for people with mild or moderate learning disabilities. Some evidence in support of the social comparisons test (Szivos-Bach, 1993) was established, but the standardisation process is likely to be slow due to the methodological difficulties which arise in conducting research with this client group, and due to the lack of comparable reliable instruments.

The author recommends further investigation of the potential of the social comparisons test as a measure of self-esteem, and replication of the study with regards to the stigma questionnaire and aspirations-expectations test to assess whether the lack of significant findings is an artefact of some aspect of this particular study. The most promising approach, however, seems likely to be development of

the social comparisons test as a multi-dimensional measure, following Robson's (1989) recommendations. An understanding of the factors which contribute to overall levels of self-esteem for this client group would be invaluable in clinical settings and in monitoring the impact of social policies at an individual level.

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**BACKGROUND INFORMATION**

Subject no: .....

1. AGE: .....

2. SEX: M / F

3. ETHNIC BACKGROUND: white UK /European .....  
black UK /European .....

4. RESIDENTIAL SITUATION: independent .....  
parental home .....  
group home (staffed) .....  
group home (unstaffed).....  
hostel .....  
supported living .....

5. WORK EXPERIENCE: current .....  
past .....

6. ANY PHYSICAL IMPAIRMENTS? Y / N

(specify .....)

## Appendix 2

Self-Rating Depression Scale (Zung, 1965)

	A little of the time	Some of the time	Quite a lot of the time	Most of the time
1. I feel down-hearted and blue. (I feel sad)				
2. Morning is when I feel the best. (I feel happiest in the morning)				
3. I have crying spells or I feel like crying.				
4. I have trouble sleeping at night.				
5. I eat as much as I used to. (I eat as well as ever)				
6. I still enjoy sex. (I enjoy thinking about men/women)				
7. I notice that I am losing weight.				
8. I have trouble with constipation.				
9. My heart beats faster than usual. (I notice my heart racing)				
10. I get tired for no reason.				
11. My mind is as clear as it used to be. (I can think about things as well as ever)				
12. I find it easy to do the things I used to. (...the things I always have done)				
13. I am restless and I can't keep still.				
14. I feel hopeful about the future.				
15. I am more irritable than usual. (I get annoyed with people easily)				
16. I find it easy to make decisions.				
17. I feel that I am useful and needed. (...and people need me)				
18. My life is pretty full. (My days are busy)				
19. I feel that other people would be better off if I were dead.				
20. I still enjoy the things I used to.				

INSTRUCTIONS: This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few days. Use the following scale to record your answers:-

1	2	3	4	5
very slightly	a little	moderately	quite a bit	extremely
or not at all				

___	interested	___	irritable
___	distressed	___	alert
___	excited	___	ashamed
___	upset	___	inspired
___	strong	___	nervous
___	guilty	___	determined
___	scared	___	attentive
___	hostile	___	jittery
___	enthusiastic	___	active
___	proud	___	afraid

#### SATISFACTION WITH LIFE SCALE

INSTRUCTIONS: Below are five statements with which you may agree or disagree. Using the 1 to 7 scale below, indicate your agreement with each item by *writing* the appropriate *number* on the line opposite that item. Please be open and honest in your responding. The scale is as follows:-

- 1 = strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 = slightly agree
- 6 = agree
- 7 = strongly agree

1. In most ways my life is close to my ideal \_\_\_
2. The conditions of my life are excellent \_\_\_
3. I am satisfied with my life \_\_\_
4. So far I have attained the important things  
I want in life \_\_\_
5. If I could live my life over again, I would  
change almost nothing \_\_\_

**Measures of Emotional Well-being**

***Adapted from Positive and Negative Affect Scale (Watson and Clark, 1988)  
and Satisfaction with Life Scale (Deiner et al, 1985)***

	A little of the time	Some of the time	Good part of the time	Most of the time
--	-------------------------	---------------------	--------------------------	---------------------

1. I feel happy
2. I am satisfied with my life.
3. I feel confident and sure of myself.
4. I find it easy to concentrate.
5. If I could live my life over again, I would not change things.
6. I feel enthusiastic.

**Social Performance Survey Schedule**

Subject .....

Please complete all items by ticking the relevant boxes, using this code:

0 - Not at all : 1 - A little : 2 - A fair amount : 3 - Much : 4 - Very much

	0	1	2	3	4
1. Has eye contact when speaking.					
2. Reacts with more anger than a situation calls for.					
3. Seeks others out too often.					
4. Shows enthusiasm for others' good fortunes.					
5. Is aggressive when (s)he takes issue with someone.					
6. Initiates contact and conversation with others.					
7. Puts him/herself down.					
8. Takes advantage of others.					
9. Makes other people laugh (with jokes, funny stories etc.)					
10. Interrupts others.					
11. Seems impatient for others to finish their remarks.					
12. Shows appreciation when someone does something for him/her.					
13. Demonstrates concern for others' rights.					
14. Reveals personal information and feelings to those with whom (s)he is close.					
15. Threatens others physically or verbally.					
16. Is able to make people who are anxious or upset feel better by talking to them.					

(continued 2)

Subject .....

*0 - Not at all : 1 - A little : 2 - A fair amount : 3 - Much : 4 - Very much*

	0	1	2	3	4
17. Makes others feel (s)he is competing with them.					
18. Hurts other people while striving to reach his/her goals.					
19. Talks repeatedly about his/her problems and worries.					
20. Asks others how they've been, what they've been up to, etc.					
21. Gets into arguments.					
22. Remembers and discusses topics previously discussed with others.					
23. Shows interest in what another is saying (eg. with appropriate facial movements, comments and questions).					
24. Gives unsolicited advice.					
25. Knows when to leave people alone.					
26. Directs rather than requests people to do something.					
27. Makes embarrassing comments.					
28. Stays with others too long (over-stays his/her welcome).					
29. Takes or uses things that aren't his/hers without permission.					
30. Shows appreciation when people seek him/her out.					
31. Blames others for his/her problems.					
32. Asks questions when talking with others.					

(continued 3)

Subject .....

0 - Not at all : 1 - A little : 2 - A fair amount : 3 - Much : 4 - Very much

	0	1	2	3	4
33. Gives positive feedback to others.					
34. Dominates conversations (s)he has.					
35. Keeps in touch with friends.					
36. Tells people what (s)he thinks they want to hear.					
37. Compliments others on their clothes, hair style, etc..					
38. Complains.					
39. Easily becomes angry.					
40. Tries to manipulate others to do what (s)he wants.					
41. Allows others to do things for her/him without reciprocating in some way.					
42. Has eye contact when listening.					
43. Stands up for his/her friends.					
44. Does not reveal his/her feelings.					
45. Shares responsibility equally with the members of groups to which (s)he belongs.					
46. Takes care of others' property as if it were his/her own.					
47. Asks if (s)he can be of help.					
48. Gets to know people in depth.					
49. Explains things in too much detail.					
50. Reevaluates his/her position when (s)he receives new information.					



(continued 4)

Subject .....

0 - Not at all : 1 - A little : 2 - A fair amount : 3 - Much : 4 - Very much

	0	1	2	3	4
51. Makes sounds (eg. burping, sniffing) that disturb others.					
52. Keeps commitments (s)he makes.					
53. Deceives others for personal gain.					
54. Directs conversation with other people towards topics in which the other person is interested.					
55. Tries to help others find solutions to problems they face.					
56. Stands up for his/her rights.					
57. Focuses conversation on his/her accomplishments and abilities.					

Thank-you for completing this questionnaire.

**WYCOMBE DISTRICT RESEARCH ETHICS COMMITTEE****APPLICATION FOR PROPOSED RESEARCH PROJECT****1. Title**

A study to assess the reliability and validity of a measure of self-esteem and perception of stigma in people with learning disabilities.

**2. Biographical Data**

Research to be conducted by **Janet Hitchen**, Clinical Psychologist in Training (Oxford (Regional) In-Service Training Course in Clinical Psychology).

Under the supervision of **Magda Sereda**, Consultant Clinical Psychologist, and **Ruth Wacholder**, Clinical Psychologist.

**3. Personal Experience**

Janet Hitchen is currently in her final year of training on the doctoral course in Clinical Psychology. The proposed study will be submitted to the course as a dissertation in July 1996. The investigator has a longstanding interest in the area of self-concept for people with learning disabilities. She has four years of experience of direct work with this client group in a number of settings and roles: residential and day services, as a care assistant, an assistant psychologist and a day care officer. She is therefore sensitive to issues which may arise in research involving client interviews and is competent in relating to the client group. In terms of research experience, she has received training in research methodology as part of the clinical course and has successfully conducted two research projects in child and learning disabilities service settings.

The supervisors named above are based at  
and are employed by the

NHS Trust.

**4a. Research Questions**

1. Does the Social Comparisons Test (Szivos-Bach, 1993) have construct validity?

Hypothesis: High self-esteem, as measured on the Social Comparisons Test, will correlate with low levels of depression as measured on the Zung Depression Inventory (Zung, 1965) and with good use of appropriate social skills, as measured by the Social Performance Survey Schedule (Matson et al, 1983). High self-esteem will not correlate with IQ, as measured by the British Picture Vocabulary Scale.

2. Does the Stigma Questionnaire (Szivos-Bach, 1993) have construct validity?

Hypothesis: High scores on the Stigma Questionnaire (indicating subjects perceive high levels of stigma) will correlate with high levels of depression, as measured on the Zung Depression Inventory and with poor use of appropriate social skills, as measured by the Social Performance Survey Schedule. High scores on the Stigma Questionnaire will not correlate with IQ.

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3. Does the Aspirations-Expectations Test (Szivos-Bach, 1993) have construct validity?

Hypothesis: High discrepancy scores, representing a large difference between subjects' aspirations and their expectations, will correlate with high levels of depression as measured on the Zung Depression Inventory and with poor use of appropriate social skills, as measured by the Social Performance Survey Schedule. High discrepancy scores will not correlate with IQ.

4. Are the Social Comparisons Test, the Stigma Questionnaire and the Aspirations-Expectations Test reliable measures over time?

Hypothesis: Test-retest scores will show a significant degree of consistency for these measures.

5. What are the relationships between other measures in the sample?

eg. Does high self-esteem (as measured by the Social Comparisons Test) correlate with low perceived stigma (as measured by the Stigma Questionnaire)? Do high discrepancy scores on the Aspirations-Expectations Test correlate with low self-esteem (Social Comparisons Test)? The study will also incorporate measures of emotional well-being, and it is hypothesised that high ratings of emotional well-being will correlate with high self-esteem and/or low perceived stigma.

#### **4b. Proposed project outline**

There has been little structured research into the self-concept of adults with learning disabilities. Research with children suggests that children with learning disabilities in mainstream schools may have lower self-esteem than those in special schools, due to their comparison with a more able peer-group (Coleman, 1983). This could be a contraindication for the current philosophy of social role valorisation in services for people with learning disabilities - the move to increased community integration for adults with learning disabilities may have negative effects on self-esteem by emphasising comparisons with more able peers.

Individual researchers have begun to explore self-esteem and self-concept in adults with learning disabilities, but to date have used different and often unstandardised approaches. This limits the generalisability of results. Oliver (1986) reported a case study assessing the self-concept of a woman with learning disabilities using repertory grids. Zetlin et al (1985) used questionnaires standardised on a normal adult population and Benson and Ivins (1992) used questionnaires adapted from the child setting. Szivos-Bach (1993) developed questionnaires to explore social comparisons and perceived stigma specifically for adults with learning disabilities. Gibbons (1985) used vignettes to explore subjects' perceptions of stigma and their use of social comparisons, and Jahoda et al (1988) used loosely structured interviews to assess perceptions of handicap and stigma.

There is clearly an important relationship between self-esteem, self-concept and mental health. The existence of standardised measures of self-esteem for adults and children without learning disabilities demonstrates a recognition of the need to address this area. At present, the field of learning disabilities lacks standardised instruments for the assessment of self-esteem, and

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lacks a broad framework to understand how people with learning disabilities view themselves and others.

On an individual level, standardised measures and an understanding of the nature of self-concept among adults with learning disabilities would be useful in clinical settings for assessing difficulties, to inform choice of treatment and to measure change over time. At the level of service policies and the social context, they would allow objective assessment of the impact of policies such as the move to increased community presence on aspects of self-esteem for the client group itself.

It appears that the measures developed by Szivos-Bach (1993) could meet some of these needs. She has drawn on other sources, such as Gibbons' (1985) work on the use of social comparisons and Oliver's (1986) repertory grid approach, as well as incorporating information from research with other populations. The measures were designed specifically for use with people with learning disabilities, thus avoiding the difficulties encountered in using standard adult instruments (Zetlin et al, 1985) or child instruments (Benson and Ivins, 1992). The Stigma Questionnaire in particular may be sensitive to the effect of changes in the social context and in service provision. For these reasons, it is proposed to test the reliability and validity of these measures in order to further the development of standardised measures of self-esteem for the learning disabled population. Further research to broaden the knowledge base can then proceed using measures which are comparable across studies.

The researcher is restricted in terms of choice of measures to test for validity as few measures have been standardised and tested on this population. The Zung Depression Scale has been shown to be reliable for adults with learning disabilities (Michie and Lindsay, 1988) and the Social Performance Survey Schedule has similarly been tested for use with carers of people with learning disabilities (Matson et al, 1983). It is hypothesised that low self-esteem will correlate with higher levels of depression and also with poorer interpersonal skills, so that these instruments can provide useful standards for testing validity.

References are included as a separate sheet.

### **5a. Concise description of research methodology**

Subjects will be contacted via local day services for adults with learning disabilities. Before contacting subjects directly, the study will be discussed with staff to ensure their understanding of and support for the study, and to enable identification of all potential subjects. Letters will be sent to clients via day centres (see attached sheet): staff will then be able to explain the letters to clients who have reading difficulties.

Data will be collected by individual sessions with subjects, using a set of five questionnaires and other measures. Sessions are expected to last between 45 minutes to 2 hours (based on Szivos-Bach, 1993). If subjects appear fatigued or wish to discontinue before all measures have been administered, data collection can be spread over two sessions. The main investigator will visit subjects in a setting familiar to them to conduct the sessions. The Social Performance Survey Schedule will be completed independently by two staff who know the subject well within two weeks of the conclusion of each interview.

In order to assess test-retest reliability, administration of the measures of self-esteem (the Social Comparisons Test, the Stigma Questionnaire and the Aspirations-Expectations Test) will be repeated at an interval of two to three months. The process of ensuring informed consent to participate will be repeated at this stage.

The measures used are:

- **Demographic data** comprising age, sex, current type of residential situation (eg. with parents, group home, hostel, supported living), current or previous work experience, ethnicity (White British, Black British, Black other, Asian, Other - terms to be based on "Guidelines for Ethnic Monitoring") and whether the client has an additional physical disability.
- **The Social Comparisons Test, the Stigma Questionnaire and the Aspirations-Expectations Test** (Szivos-Bach, 1993) have been used previously with young adults with learning disabilities and will be tested further in this study.
- **The Zung Depression Inventory** (Zung, 1965, adapted by Michie and Lindsay, 1988) and
- **the British Picture Vocabulary Test** are established measures.
- **Measures of emotional well-being** have not been standardised for this population. The items to be used have been selected from two scales, the Positive and Negative Affect Scale (Watson and Clark, 1988) and the Satisfaction with Life Scale (Deiner et al, 1985). It is proposed to incorporate these items to explore the relationship between emotional well-being and perception of stigma / self-esteem in a preliminary way. Prior to beginning the study, the items will be piloted with a small group of clients to ascertain whether they can be used by this client group.
- **Pre-test items** will be used to ascertain whether the subject can allocate choices on a three and five-point scale. Examples are given in the interview schedule in the appendices. This allows the researcher to assess whether the client will be able to understand the nature of the questions asked.
- **Social Performance Survey Schedule** (Matson et al, 1983). This will be completed by two staff familiar with each client, and has been standardised for use with this client group.

It is important to be aware that interviews with clients may highlight cases of distress, high levels of depression or disclosures of abuse. In such cases, the researcher will discuss with the client the possibility of requesting professional input and will endeavour to gain the client's permission to discuss the problems with a keyworker, GP or other named person. In cases of disclosed abuse or where harm to the client is judged likely but the client refuses permission to discuss this, the researcher is bound professionally and ethically to refer the client on to the appropriate service and will explain this to the client.

#### **5b. Number and type of participants**

30 to 50 adults with mild or moderate learning disabilities. Participants will have some verbal abilities using spoken English, eg. being able to answer open-ended questions in a form other than "yes/no"; or, if non-verbal, will demonstrate comprehension of speech and an ability to allocate choices on a

three and five-point scale (using the pre-test items described in 5a). Subjects will include both males and females between the ages of 18 and 65 years.

#### **5c. Likely duration of project and where it will be undertaken.**

It is proposed that the study will be conducted between November 1995 and July 1996. Data collection will take place in High Wycombe and Amersham, the researchers being based in High Wycombe.

#### **5d. Data Collection Procedures.**

The measures to be used are included on additional sheets, other than the British Picture Vocabulary Test which involves use of a booklet of sets of pictures: subjects are asked to indicate by pointing which of a set of pictures corresponds to a word spoken by the investigator. This is used to give an indication of IQ.

#### **5e. Data analysis**

Data will be analysed using the SPSS-X computer package.

Descriptive statistics - means and ranges.

Data from the questionnaires will be analysed using parametric tests if possible. Correlations (Pearson's product moment) will be used between measures, to assess validity. Analysis of Variance will be used to analyse elements within the Social Comparisons Test and may be used to assess test-retest reliability for this measure. Test-retest reliability will be analysed using separate correlations for the other measures.

It may be appropriate to use non-parametric tests to analyse results according to categories of demographic data.

#### **6a. Information to patients**

A letter providing information and inviting clients to participate in the study is included as an additional sheet. (Space has been left for a photograph and Makaton symbols may also be added). There are particular difficulties in ensuring the comprehension of information with this client group. A number of procedures are built into the design of the study to ensure that consent is informed. Firstly, staff working with the clients will be aware of the study and can therefore read the information sheet to clients if necessary, discuss queries and act on the client's behalf to seek clarification from the investigator if necessary. The information sheet for staff is also included in the appendices. Secondly, the main investigator will explain the purpose and content of the study again to subjects who agree to participate, and check that they still consent to be involved. She will talk around the issues of withdrawing consent and confidentiality with subjects to check their understanding that they can withdraw at any stage and that information will be treated as confidential and recorded so that the subject cannot be identified. Before proceeding with the administration of measures, she will also go through the form for written consent (section 6b) verbally with the subject. Subjects can sign this or mark it if they are unable to write.

#### **6b. Written consent**

The form to be used is included as an extra sheet.

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**7. Material / financial benefit from the study.**

The research is not sponsored and will not provide financial benefit.

**8. Storage and Confidentiality of Data.**

Data collected from interviews will be marked using subject codes rather than names. A list of clients contacted, from which subject codes can be allocated, will be kept in a locked filing cabinet at 309 Cressex Road along with signed consent forms.

**9. Research project sponsor.**

The proposal has been read and is supported by Magda Sereda, Consultant Clinical Psychologist.

**10. Signature of applicant.**

*Janet M. Wicks*

11/11/95

Tel: (

***Local Research Ethics Committee***

16 November 1995

Ms Janet Hitchin  
Clinical Psychologist in Training  
Isis Education Centre  
Warneford Hospital  
Headington  
Oxford

Dear Ms Hitchin,

**REC269 - A study to assess the reliability and validity of a measure of self-esteem and perception of stigma in people with learning difficulties**

Thank you for submitting the above study to the ' ' LREC where it was considered at the recent meeting. We should like to congratulate you on a well-thought out and well-presented study which pays particular attention to the sensitive issues involved with doing research on this vulnerable group of patients.

Our only concern was whether you would be able to interview upto 50 patients for two hours at a time between December and March when you are only based in on one day per week. Have you consulted a statistician about the number of clients you need to interview and, if necessary, will you be able to extend the time limit in order to make the study scientifically valid?

I look forward to your reply and will then be able to give you formal ethical approval.

Yours sincerely,



PP Dr.

Chairman, Research Ethics Committee



Isis Education Centre,  
Warneford Hospital,  
Warneford Lane,  
Headington,  
Oxford,  
OX3 7JX.

20th November, 1995.

Dr.

Amersham.

Dear Dr.

**REC269 - A study to assess the reliability and validity of a measure of self-esteem and perception of stigma in people with learning difficulties.**

Thank-you for your letter of 16th November. I was pleased to receive such positive comments from the LREC. I am writing to confirm that I am aware of the tight time constraints for data collection within my proposal. I have consulted several people, including Dr. Paul Griffiths, a statistician based at Oxford University, about the size of sample necessary for valid results, and 30 would be the minimum number I need to see. I will have at least 10 extra days between December and March for data collection, in addition to my allocated weekly day in . If necessary, it will also be possible to extend follow-up sessions into April and May 1996.

I hope that this is a satisfactory answer to your queries. I look forward to receiving your reply.

Yours sincerely,

Janet Hitchen,  
Clinical Psychologist in Training.

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**Local Research Ethics Committee**

23 November 1995

Ms Janet Hitchen  
Clinical Psychologist in Training  
Isis Education Centre  
Warneford Hospital  
Headington  
Oxford OX3 7JX

Dear Ms

**REC269 - A study to assess the reliability and validity of a measure of self-esteem and perception of stigma in people with learning difficulties**

Thank you for your letter of 20th November, which satisfactorily answers our concerns. I am now happy to grant formal ethical approval for this study. Please note that this approval is for a period of two years only.

We would be grateful if you would complete the enclosed R & D Project Details proforma and return it to the Anglia and Oxford RHA using the envelope provided.

Good luck with this study.

Yours sincerely



PP Dr

Chairman, Research Ethics Committee

## INFORMATION SHEET FOR STAFF

### PROPOSED STUDY INTO THE SELF-CONCEPT OF ADULTS WITH LEARNING DISABILITIES.

**About me:** I am a clinical psychologist in my third year of training at Oxford. Prior to starting the course, I spent four years working with adults with learning disabilities in residential and day-care settings. I have an ongoing interest in working with this client group.

**About the study:** I am required to carry out research as part of my course, and this provides an opportunity to focus on issues important to the quality of life of people with learning disabilities. The study is supervised by Magda Sereda and Ruth Wacholder, clinical psychologists based in .

**Why look at self-concept?** The way we think about ourselves and others affects our feelings and behaviour. People who are seen as "different" and experience stigmatisation might develop low self-esteem, leading to unhappiness or isolation. This is clearly a possibility for lots of people with learning disabilities, but up to now, little work has been done to find out if this is true, who is at risk and what factors protect clients' self-esteem. The study is designed to begin to address these issues.

**Who would be involved in the study?** To get meaningful results, it would be useful to see as many clients as possible within the age range 18 to 65. Anyone with some verbal understanding could be included in the study: speech isn't necessary provided they can indicate yes/no or choose one out of four or five items. No-one would be forced to take part, and clients could withdraw at any stage if they wished.

#### ***Proposed stages of the study (October 1995 to March / April 1996):***

1. I will meet with staff to discuss the study in more detail, to answer queries and get feedback about the viability of the study.
2. If agreed, letters will be sent to clients inviting them to take part. The letters will introduce me and the study briefly and describe what clients could expect to happen in meetings. It is hoped that staff could offer support at this stage in reading / explaining the content of letters if necessary.
3. Individual meetings with me, within the centre if possible, or elsewhere if the client prefers. I will explain the study further and check that the client is still willing to be involved. Consent forms would be used at this stage, with a copy for the client as well as the researcher. As well as providing a record of clients' agreement to participate, the consent forms will re-state that clients can leave the study at any stage if they wish.

Meetings will last between 45 minutes and 2 hours, and some clients may prefer to meet for two shorter sessions. The study uses a number of measures which are completed by talking around issues or by the client indicating preferences using visual aids. Some examples of the measures are

included on separate sheets. The measures look at how people rate themselves and people they know on different characteristics, how much they experience or perceive stigma, their emotional state and their aspirations / expectations. It is hoped that the opportunity to explore some of these issues will be interesting for clients as well as providing useful information for the study.

4. After these measures have been completed with the client, two staff members who know the client well will be asked to complete a questionnaire about interpersonal behaviour. The questionnaires should take just 10 to 20 minutes to complete, and will provide another source of information to strengthen the findings without overloading the clients with more measures. I would ask that staff complete these forms without consulting with each other.

5. It will be necessary to repeat some of the measures with clients two to three months later. Again, clients would be asked if they are happy to participate. Follow-up sessions are likely to be shorter than the initial sessions.

6. The results would be fed-back to staff and clients to enable discussion of issues arising and to evaluate clients' experience of the study.

***Practical considerations:*** I hope to arrange meetings for Tuesdays, though I will also be available on occasional other days. The sessions would be confidential and therefore require the use of a small room if at all possible. I would be aiming to carry out client interviews between early December and late March, in more than one location.

***Potential benefits to the service:*** It is hoped that involvement in the study will be of interest and practical use to clients and staff. It may be that clients will wish to extend their consideration of some issues into discussion groups in the centres. Issues raised are likely to tap into what are the actual effects of increased community presence on self-esteem and of clients' own awareness of self-advocacy needs and group identity. If enough clients agree to participate, the results will provide a comprehensive picture of the way clients see themselves and others in this locality, information which could give a unique perspective into the impact of service planning on their quality of life.

***Ethical issues:*** Clients must consent freely to be involved in the study and can withdraw at any stage. All sessions will be treated as confidential by the researcher, and recorded information will not identify individuals by name. Although the researcher will not be raising sensitive issues such as abuse or thoughts of suicide, there is a possibility that a few clients will disclose distressing facts. If this happens, and only after discussion with the client, I will inform the appropriate member of staff, GP or social worker so that appropriate action can be taken.

Thank-you for your consideration of this study. I look forward to discussing it in more detail.

**Janet Hitchen**  
**Clinical Psychologist in Training.**

## Psychology Department

November 1995

Dear

I am Janet Hitchen. I have visited . a few times, so you might recognise me from my photograph. I work with Magda Sereda and Ruth Wacholder. I am a trainee psychologist.

I am interested in finding out how people think about themselves, friends and other people they know. I'd like to meet with you to find out if you would like to help me in my work. This means



we would meet at the centre to talk in private, just you and I. I would ask you some questions and we would talk about how you feel and how you think about a few people. Everything we talk about will be private and confidential, so I won't tell anyone else about it unless you want me to.

If you agree to meet me, you would miss 2 or 3 sessions at the centre. Staff have said that this is OK. But you can change your mind at any time and say you don't want to meet again, and that's OK too. I won't talk about it with staff unless you ask me to and it won't affect your sessions at the centre.

You can ask me questions about my work before you decide whether to help me in my work. You can use the form below to get in touch with me or ask your keyworker to get in touch with me. Staff know that I want to meet people at so you can ask them about me too.

I look forward to hearing from you.  
Best wishes,

**Janet Hitchen**  
**Clinical Psychologist in Training.**

**To Janet Hitchen.**

I have read your letter about your work finding out how people think about themselves and people they know.

I would/ would not like to meet you to talk more about this.

Signed: .....

Date: .....

## STUDY INTO THE SELF-CONCEPT OF ADULTS WITH LEARNING DISABILITIES.

### INFORMATION FOR PARENTS / CARERS

The managers and staff at                      Centre,                      and  
Centre,                      have given their permission for this study to take place in  
these settings. Some clients will be receiving letters about the study inviting  
them to take part: this sheet is to ensure that the parents and carers of  
those clients are aware of this.

The study is intended to develop ways of assessing how people perceive  
themselves in relation to others. Similar measures are often used in clinical  
settings for adults and children without learning disabilities, but there is a  
need to develop alternative measures which are appropriate for use with this  
client group.

The study will be conducted by Janet Hitchen, a Clinical Psychologist in her  
final year of training in Oxford. She is supervised by Magda Sereda and  
Ruth Wacholder, Clinical Psychologists based at

. Janet has considerable experience of working with adults with  
learning disabilities, having spent 4 years working in residential, community  
and day care settings prior to beginning her course.

The study is expected to run between December 1995 and April 1996. It is  
hoped that between 15 and 25 clients from each centre will agree to take  
part. These clients will meet with Janet for one or two sessions of about an  
hour initially, followed by a shorter session two months later to repeat some  
measures. Clients will be asked to give ratings on a number of measures  
which Janet will talk through with them - they are not required to read or  
write themselves. It is expected that many clients will enjoy the process of  
talking through the issues raised.

Before commencing sessions, Janet will check that the client understands that  
they can choose not to take part, and that they can leave at any time if  
they wish. Sessions will be confidential and records will use codes rather  
than names so that clients cannot later be identified. The purpose of the  
study is to get an overview of the area for the client group, rather than to  
focus on individuals' answers. The results will be fed back to the staff and  
clients if possible when the study has been completed.

If you have any questions or comments about the study, please contact Janet  
Hitchen at the Psychology Department,  
or 'phone                      . Please leave a telephone number or address so  
that Janet can get back to you.

*Janet Hitchen*

JANET HITCHEN  
Clinical Psychologist in Training.  
November 1995.

**CONSENT FORM**

**I agree to be involved in the study being carried out by Janet Hitchen, Clinical Psychologist in Training, looking at the way people think about themselves and others, and how this affects their feelings.**

Have you read the invitation letter, or someone has read it to you? YES/NO

Have you had a chance to ask questions and talk about the study? YES/NO

Were all your questions answered? YES/NO

Who have you spoken to?  
.....

Do you know that you can change your mind and say you don't want to be in the study at any time? YES/NO  
You don't have to say why you changed your mind.  
Janet won't talk about it with staff at the centre unless you ask her to.

Signed: .....

Name: .....

Date: .....

## ***INTERVIEW SCHEDULE***

1. Check consent is informed, subject to sign consent form.
  2. Introductory questions to check comprehension and orientation.  
eg. What do you do here?  
Where do you live? (subjects excluded if answer yes / no).
  3. Complete background information sheet.
  4. British Picture Vocabulary Scale.
  5. Pre-test questions to check ability to use 5 - point scale.  
eg. Using the scale (researcher demonstrates), show me how much you agree with these statements:  
I am good at making tea.  
I tell funny jokes.  
I can't get up in the mornings.
  6. Social Comparisons Test.
  7. Stigma Questionnaire.
  8. Pre-test questions to check ability to use 3-point scale.  
eg. Show me which one of these (I would like to, I don't know, I wouldn't like to) fits for each sentence I say:  
Go to the pictures this week.  
Go on holiday.  
Get stuck in a traffic jam on the way home.
  9. Aspirations-Expectations Test.
  10. Zung Depression Scale (adapted).
  11. Measures of Emotional Well-being.
- After interview is completed,
12. Social Performance Survey Schedule (staff).



### Additional tables of results - T-tests for independent samples

Kolmogorov-Smirnov tests indicated no evidence that data were not normally distributed for these variables for each analysis, enabling the use of parametric analyses.

Table A: Comparison of means according to centre

Centre	N		Mean		SD		T	d.f.	p
	1	2	1	2	1	2			
Age	15	15	34.13	40.6	13.42	11.95	-1.39	28	.17
IQ	15	14	55.20	60.71	22.22	24.53	-0.64	27	.53
Self-score	15	15	91.1	95.33	13.55	11.02	-0.94	28	.36
Friend	15	15	83.9	91.67	15.78	15.31	-1.37	28	.18
Other	15	15	101.33	104.60	11.77	7.67	-0.90	28	.38
Ideal	15	15	104.07	107.73	11.76	8.92	-0.96	28	.34
Stigma	15	15	26.73	26.20	6.76	8.19	0.19	28	.85
Retest-Self	11	12	89.82	94.00	14.55	12.82	-0.73	21	.47
Retest-Friend	11	12	84.73	92.25	14.06	15.00	-1.24	21	.23
Retest-Other <sup>a</sup>	11	12	92.55	104.83	20.46	6.03	-1.92	11.59	.08
Retest-Ideal <sup>a</sup>	11	12	100.45	111.83	19.05	6.82	-1.87	12.33	.09
Retest-Stigma	11	12	24.45	24.33	7.03	7.27	0.04	21	.97
Zung	15	15	41.13	39.33	5.37	9.99	0.61	28	.54
SPSS <sup>a</sup>	15	11	121.27	141.14	37.26	22.55	-1.69	23.33	.11

<sup>a</sup>Levene's test for equality of variances was significant, therefore an approximate t-test assuming unequal variances was performed for these variables.

The analyses found no significant differences between subjects from each day centre on these variables.

Table B: Comparison of means according to gender

Gender	N		Means		SD		T	d.f.	p
	M	F	M	F	M	F			
Age	17	13	37.71	36.92	14.04	11.22	0.16	28	.87
IQ	16	13	56.88	59.08	28.15	15.92	-0.25	27	.80
Self	17	13	92.26	94.46	12.60	12.35	-0.48	28	.64
Friend	17	13	83.74	93.08	16.79	13.12	-1.65	28	.11
Other	17	13	103.53	102.23	10.70	9.12	0.35	28	.73
Ideal	17	13	105.24	106.77	10.17	11.09	-0.39	28	.70
Stigma	17	13	24.65	28.85	7.52	6.74	-1.58	28	.12
Retest-Self	12	11	92.42	91.55	14.16	13.47	0.15	21	.88
Retest-Friend	12	11	84.92	92.73	12.99	16.03	-1.29	21	.21
Retest-Other	12	11	101.17	96.55	11.95	19.39	0.69	21	.50
Retest-Ideal	12	11	105.50	107.36	11.41	18.53	-0.29	21	.77
Retest-Stigma	12	11	23.50	25.36	6.56	7.63	-0.63	21	.54
Zung	17	13	39.24	41.54	9.62	5.04	-0.78	28	.44
SPSS	13	13	128.73	130.62	31.65	35.33	-0.14	24	.89

The analyses found no significant differences between subjects according to gender on these variables.

Table C: comparison of means according to residential situation

	N		Mean		SD		T	d.f.	p
	PH <sup>c</sup>	Other	PH <sup>c</sup>	Other	PH <sup>c</sup>	Other			
Age <sup>a</sup>	19	11	30.95	48.45	7.34	13.15	4.06	13.69	.001
IQ	19	10	60.84	52.20	26.02	15.91	-0.96	27	.35
Self <sup>b</sup>	19	11	94.82	90.45	12.62	11.84	-0.93	28	.36
Friend <sup>b</sup>	19	11	88.61	86.36	17.80	12.17	-0.37	28	.72
Other <sup>b</sup>	19	11	102.11	104.45	9.23	11.27	0.62	28	.54
Ideal <sup>b</sup>	19	11	105.95	105.82	11.40	8.99	-0.03	28	.98
Stigma	19	11	28.32	23.27	7.81	5.52	-1.88	28	.07
Retest - Self <sup>b</sup>	15	8	92.67	90.75	13.08	15.17	-0.32	21	.75
Retest - Friend <sup>b</sup>	15	8	88.20	89.50	15.09	15.02	0.20	21	.85
Retest - Other <sup>b</sup>	15	8	95.73	105.00	18.60	4.84	1.37	21	.19
Retest - Ideal <sup>b</sup>	15	8	105.20	108.63	17.73	7.78	0.52	21	.61
Retest - Stigma	15	8	25.93	21.50	7.00	6.41	-1.49	21	.15
Zung <sup>a</sup>	19	11	39.74	41.09	6.07	10.72	0.38	13.80	.71
SPSS	18	8	133.92	120.13	28.43	41.80	-0.99	24	.33

<sup>a</sup> Levene's test for equality of variances was significant, therefore an approximate t-test assuming unequal variances was calculated for these variables. <sup>b</sup> comparison figures from social comparisons test <sup>c</sup> parental home

The analyses show a significant difference in age between participants living with their parents and those living elsewhere. Other analyses were non-significant.

Table D: comparison of means according to work experience

	N		Mean		SD		T	d.f.	p
	Work	None	Work	None	Work	None			
Age	17	13	33.06	43.00	11.85	12.45	-2.23	28	.03
IQ	17	12	63.82	49.42	27.20	12.28	1.71	27	.10
Self <sup>a</sup>	17	13	95.91	89.69	9.16	15.21	1.39	28	.18
Friend <sup>a</sup>	17	13	84.79	91.69	17.42	12.95	-1.20	28	.24
Other <sup>a</sup>	17	13	103.18	102.69	10.40	9.61	0.13	28	.90
Ideal <sup>a</sup>	17	13	106.82	104.69	7.89	13.29	0.55	28	.59
Stigma	17	13	26.76	26.08	8.07	6.66	0.25	28	.81
Retest - Self <sup>a</sup>	13	10	96.08	86.70	7.87	17.60	1.57	11.77	.14
Retest - Friend <sup>a</sup>	13	10	89.00	88.20	12.10	18.31	0.13	21	.90
Retest - Other <sup>a</sup>	13	10	99.85	97.80	12.61	19.78	0.30	21	.77
Retest - Ideal <sup>a</sup>	13	10	107.92	104.40	11.05	19.29	0.55	21	.59
Retest - Stigma	13	10	23.00	26.20	7.48	6.20	-1.09	21	.29
Zung <sup>b</sup>	17	13	38.59	42.38	5.15	10.39	-1.21	16.49	.24
SPSS	17	9	123.26	141.78	34.42	27.50	-1.39	24	.18

<sup>a</sup> comparison figures from social comparisons test    <sup>b</sup> Levene's test for equality of variances was significant, therefore an approximate t-test assuming unequal variances was calculated for these variables.

The analyses show a significant difference in age between participants with current or previous work experience and those with no work experience. Other analyses were non-significant.

Table E: Kendall's Tau Correlation Coefficients

These results are consistent with the Pearson's product moment (Table 3.7, main text) for variables reported in both tests.

Self	-.10											
Friend	-.04	.43***										
Other	.02	.28*	-.03									
Ideal	.01	.61***	.18	.36**								
Stig	-.25	-.33*	-.08	-.15	-.38**							
Asp	-.21	.02	-.21	-.02	.01	.05						
Exp	-.28*	-.19	-.22	.01	-.10	.29*	.57***					
Diff (A-E)	.05	.18	.07	.05	.11	-.24	.37**	-.15				
Well-being	.02	.43***	.27*	.12	.30*	-.05	.01	-.09	.05			
SPSS	.12	.09	.20	.22	.05	-.06	-.30*	-.36*	.09	.02		
Zung	.00	-.38**	-.09	-.20	-.33*	.37**	-.04	.13	-.34*	-.28*	.04	
IQ	-.03	.09	-.08	.06	.09	-.10	-.13	-.12	.16	.17	.12	-.03
	Age	Self	Friend	Other	Ideal	Stig	Asp	Exp	Diff (A-E)	Well-being	SPSS	Zung

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$

